ENGAGING COMMUNITIES IN HEALTH GEOGRAPHY?

ASSESSING THE STRATEGY OF COMMUNITY-BASED PARTICIPATORY RESEARCH

by

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Abstract

Community-based participatory research (CBPR) positions community members on an equal footing with their academic colleagues and makes them responsible for the decisions which shape the direction and substance of research. The approach is founded on ideals of empowerment and the raising of critical awareness amongst stakeholders while contributing to social and community change.

This thesis examines the practice of CBPR; specifically, the inconsistencies between its ideals and the achievement of meaningful outcomes, and its relative absence within health geography. While the thesis relies most heavily on theories of social capital for its conceptual framing, it also draws on three key concepts stigma, and critical and oppositional consciousness. Three CBPR case studies were initiated to uncover the challenges, benefits, and shortcomings of the approach involving people living with HIV/AIDS, persons with disabilities, and residents of social housing. The projects were evaluated using a range of strategies including participant observation, interviews with key stakeholders, questionnaires, and focus group discussions. The implementation of these projects ranged in success from being sidelined by managerial difficulties, community mobilization efforts proving unsuccessful, to a fully realized CBPR case study.

The case studies illustrate the tenuous position of a researcher engaged in grassroots community mobilization and the need for core levels of social capital to precede the researcher's intervention. Interviews with CBPR stakeholders exposed the sense of purpose and value of being united against a given cause and even the social benefits of connecting with others. The interviews brought into question the imposition of stringent research expectations upon community members who may face multiple barriers to carrying out research and gain little benefit from the practice. I conclude by suggesting that CBPR is a long way from being the perfect marriage of academia and community, failing adequately to meet the needs of both parties. In particular, the third case study demonstrates that stakeholders are critically aware of issues that affect their lives, their capabilities to carry out research and the roles that the researcher might play. Ultimately, this raises questions about what role CBPR might play in community mobilization, especially when the resources of groups are limited socially, economically and politically.

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Statement of Originality

I hereby certify that all of the work described within this thesis is the original work of the author. Any published (or unpublished) ideas and/or techniques from the work of others are fully acknowledged in accordance with the standard referencing practices.

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Chapter One

Introduction

Within contemporary geographic and social science research, ideals of neutrality and objectivity on the part of the researcher are being widely questioned and partiality and subjectivity are increasingly accepted as an inevitable ingredient in research - albeit an ingredient best made explicit. It is this assumption of neutrality, or 'disinterestedness', on the part of the researcher which is one of the bases Wallerstein (2004) identifies as contributing to the public's trust in researchers as purveyors of the 'truth'.[1] If we can no longer assume that researchers are disinterested, if we see that they are invested in the outcomes of science through their research grants, their epistemologies, and their politics then how can we continue to put faith in what we understand as 'science' not to be tainted by the researcher's position?

Participatory research brings into question some of these fundamental assumptions of geography and the social sciences, such as what constitutes valid knowledge, and demands that we take a critical look at the distribution of power upon which academic

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[1] "...we trust the relative disinterestedness of the scientist. We believe that scientists (unlike, once again, theologians, philosophers, and purveyors of folk wisdom) are psychically ready to accept any truth that emerges from an intelligent reading of the data without feeling the need to hide these truths or to distort them or deny them (Wallerstein, 2004:10)."

research is based. We are led to ask: “What implications does taking a critical perspective of the research we conduct have on the validity of the knowledge that we produce?”[2] We must also ask: “Whether ‘valid’ scientific knowledge can be produced by non-academics?”[3] and “can non-academics benefit from being involved in the research process”? These critical research considerations follow on from feminist traditions of questioning the dominant way of knowing and are necessary for epistemological and methodological development (Eyles, 1993). This thesis reflects on the nature of geographic and social science research and the implications of involving community members in a process of research that has historically been restricted to the activities of academic researchers

To elucidate the goals of the thesis I will begin with an overview of the practice of participatory research and its implications for communities and researchers. The ideals underpinning the participatory process will be discussed with reference to the positive outcomes of community involvement identified by participatory researchers and social capital theorists. The goals of this thesis will be discussed in-depth, as will the process of situating participatory research within the context of health geography. The introduction will conclude with an overview of the themes to follow in each of the chapters.

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[2] In reference to the use of qualitative methods Kobayashi (2001:56) explains that through a critical perspective we see research “as a basis for challenging dominant ways of understanding, and for exploring the contradictions that give rise to social inequities and patterns of marginalization. It demands an ethical positionality.”

[3] Wallerstein (2004:10) believes that in conjunction with disinterestedness it is the qualification of researchers to be the key factors in leading us to place trust in the scientific community: “We assume that specialized knowledge is difficult to acquire, demanding long and rigorous apprenticeship. We put our faith in formal institutions, which in turn are evaluated by reliability scales... In short, we trust that professionals have appropriate skills, and most particularly the skill to evaluate new truth claims in their fields...”

1.1 PARTICIPATORY RESEARCH & ITS DISCONTENTS

> Making the decision to try participatory research was doing things backwards. Standard research textbooks advise social scientists to first identify a research problem and then select an appropriate method. Instead I had an approach in search of a problem.
>
> (Maguire 1987:111)

My decision to adopt a participatory research approach arose out of both a desire to be involved in research with social pertinence and an interest in exploring alternative methods of knowing. While conducting interviews and working with the results of my master's thesis I became acutely aware of how one-directional the relationship is between the participants and researcher within the bulk of traditional research. Feminist epistemology suggests that the interview process should be an empowering experience for the participant as the researcher is valuing and validating their experiences (Dunn, 2000); however, this approach does not promote a particularly deep level of empowerment and commitment to the participant and our ability to know what is really going on during research encounters has come into question (Valentine, 2002:125).

In reviewing the community-based participatory research (CBPR) literature, I found there was no precedent for its use in health geography; this led me to question whether it is an approach with the potential to enrich health geography research or whether it is better suited to disciplines such as social work where the tradition of 'hands-on' research is much stronger.[4] To answer these questions CBPR case studies were promoted and

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[4] Coulton (2005) identifies social workers as those who should be at the forefront of understanding how and why communities change because of the fundamental connection between communities and the practice of social work.

analysed and are described through an 'emerging narrative' in which the participatory process is discussed with reference to the pertinent literature. Insight gained from participant observation, interviews, and focus group-style discussions with research stakeholders contributes to an evaluation of the effectiveness of CBPR and its relevance to knowledge production within health geography. The research addresses a need to appraise critically the participatory research process for the furthering of geographic knowledge and enhancing understanding and involvement of communities in the research process.

In participatory research, the researcher becomes a partner in the production of research working with communities to solve problems and achieve collective action (Park, 1993). Participatory research works toward ensuring the community has the tools with which to carry out research and uses the results to work toward positive social change. At the very least, a participatory approach allows community members contact and support with people in shared circumstances with personal growth potentially resulting from such contacts. Ideally, the participatory approach also results in the successful production of research in which participants gain the knowledge and skills to overcome sources of oppression in their environment.

The collaborative nature of participatory research creates many incompatibilities with traditional academic research processes as the researcher, in favouring community needs over the achievement of academic interests, does not have control over the direction that the research will follow (Heaney, 1993). On an ideological level, the devolution of power to the community is most starkly in opposition to positivist ideals of research. Not only are researchers deemed value-laden but those conducting the research – the community – are not 'qualified' to do so, they are emotionally involved in their research topic, and are politically motivated. How then can research of ‘value’ (i.e., objective and impartial research) be produced by individuals motivated by the achievement of political ends?

> ...professional training has often, perhaps almost always, been so organized as to omit important elements in their analyses or to distort such elements. This is only in part a function of the social bases of recruitment of scientists. To be sure, to the extent that scientists are disproportionately drawn from socially dominant strata worldwide, it may be thought that the selection of problems may suffer distortion.
>
> (Wallerstein, 2004:10)

The emergence of a cohort of researchers acting outside of traditional institutions signifies a challenge to positivist paradigms and brings into question many of the assumptions upon which our institutions of research are founded. Constructing an alternative research epistemology necessitates a critical analysis which simultaneously builds on and distances itself from the dominant ideology: “The critical analytic process is one of deconstructing taken-for-granted concepts and theoretical relationships by asking how these taken-for-granted elements actually relate to wider oppressive structures and how these structures legitimate and conceal their oppressive mechanisms (Eyles, 1993:51).” A critical analysis of the dominant research paradigms and the institutions which foster them turns up a cycle of self-legitimation as those with the authority to conduct research (academic qualifications) are also those who determine what constitutes valid research through such mechanisms as peer review processes established to vet access to academic journals and research funding. While many of these practices are heavily ingrained within the institutions of research there is increasing evidence that alternative research paradigms are being acknowledged through such changes as the broadening of the review criteria of research ethics boards to allow for participatory research methodologies.

Participatory research sits uncomfortably alongside dominant research paradigms in geography and the social sciences as its collaborative nature produces research results which cannot be easily assigned to one individual. The researcher is unable to define clearly her/his input into the process or to claim authorship over publications, thereby negating the academic definition of a successful researcher. Furthermore, PhD requirements clearly state the need for research to be owned by and attributed to one individual (Heaney, 1993) who is being evaluated on his/her ability – not a community's - to produce research. Participatory research can be evaluated in terms of other research outputs, such as, the achievement of social change, or the sense of empowerment gained by community stakeholders. Such benchmarks, however, cannot be directly attributed back to the researcher, as this would suggest the research process had not been collaborative, which in turn would be a participatory failure! The question then arises as to how one can meet the requirements of a PhD to contribute new knowledge to a field when the research process cannot be controlled or the data claimed as one's own?

> A doctoral student working on a dissertation cannot afford the luxury of working with a community on a community's timetable and with the possibility that the project will be called off or take on a different set of goals – in fact, become a different project. Financial considerations and doctoral committees conspire to impose rigid controls on the student's proposal, research, and its allowable conclusions, all of which not only inhibits community participation in the project, but effectively prohibits community control over the outcomes.
>
> (Heaney, 1993:45)

This thesis gets around the 'problem' of participatory research as a collaborative initiative by investigating the value of the participatory research process and its implications for community stakeholders. What begins to emerge is a picture of participatory research as a set of ideals which challenge the academic system and its foundation of traditional, if not positivist, approaches to social science research.

Untangling the contradictions of carrying out ‘scientific’ research with lay people, balancing the time-span of participatory research within the framework of a PhD, and re-conceptualising the goals of geographic and social science research are all issues discussed in this thesis. For now, I want to expand briefly on the ideals of participatory research and how these are deeply intertwined with present thinking on the subject of social capital.

1.1.1 Participatory Research & Social Capital Theory

The rising presence of social capital theory in health geography and the social sciences in recent years has added impetus to the potential for communities to benefit positively from the process of research, rather than simply from the outcomes. Social capital theory emphasizes the role of social networks in improving the health of individuals and society; social capital is believed to grow by fostering education, cooperation and trust by investing time and energy into one’s community (Sobels et al., 2001). Fostering social capital should be intrinsic to participatory research, given the aim of CBPR to achieve community empowerment. We must, however, question whether participatory research is adequate to produce social capital, particularly given that there is so little concrete knowledge regarding how it is produced. Participatory processes provide us with the opportunity to explore the conditions under which social capital may (or may not) be fostered and to characterise its evolution over time. One of the key foci of the thesis, therefore, is to examine the nature of relationships within community-based participatory research and the implications of these relationships for the wider community.

1.2 THESIS GOALS

The imperative that the outcomes of participatory research be assigned to the community, and my own interest in the merits of participatory research as an investigative process, mean that the goals of this thesis are focused on the process of CBPR rather than its outputs. I examine whether the ideals espoused by participatory researchers are achievable and, more broadly, what benefits CBPR brings to the social sciences and, more specifically, health geography. The goals of the research are:

1. To evaluate the effectiveness of community-based participatory research. This will be achieved by answering the following research questions:

a) Does the process of 'conscientization' , as advocated by Freire (1970) really occur in participatory research?

b) Can the goal of collaborative research be realistically achieved throughout all aspects of the research process?

c) Does the participatory process result in useful learning for both the researcher and the community stakeholders?

d) How compatible is the role of academic researcher with that of CBPR facilitator/activist?

2. These overriding research questions will also be drawn on to assess how useful participatory research is to the sub-discipline of health geography. Specifically, I am interested in:

a) Whether employing CBPR may enrich existing knowledge in the realm of health geography.

b) What are the difficulties of applying participatory research to health geography, particularly within the context of academia?

The success and effectiveness of CBPR has implications for the ways in which research is carried out and for the future direction of geographic and social science research. The popularity of participatory approaches is contributing to a shift in the kinds of questions we are asking as researchers and the methods through which we gain our answers. The widespread adoption of qualitative methodologies and politically driven epistemologies has set the stage for a shift to the adoption of participatory methods within geography and the social sciences. The present research goes further to examine the future for community-based participatory research; an approach in which the impetus for the research focus originates with communities.

1.4 THESIS STRUCTURE

This thesis can broadly be understood as methodological; my concern is with CBPR as a research approach and this focus, in addition to the use of case studies, means it is organized in a slightly different manner from most theses. The first four chapters are concerned with providing a conceptual and theoretical basis for understanding CBPR. Chapters Five to Seven focus on the context of the present study describing the methods used and the nature of the case studies. The final four chapters discuss the results of the case studies and reflect on the nature of CBPR. Specifically, each chapter is concerned with the following major themes:

Chapter Two: The Principles of Community-Based Participatory Research

Chapter Two is concerned with situating CBPR in the context of the range of participatory approaches currently in use. Community-based participatory research is located at the more community-driven end of the spectrum of participatory approaches and differs significantly from many of the participatory methods such as Photovoice and participatory mapping which are gaining popularity in geography. The values and goals which distinguish CBPR from other participatory approaches are discussed with particular reference to the work by educator Paulo Freire. Finally, links are made between the goal of CBPR, to achieve social change, and the theoretical grounding of the thesis in social capital theory and particularly the work of Pierre Bourdieu.

Chapter Three: A Participatory Research Paradigm for Health Geography

The third chapter examines the concept of participatory research in relation to the epistemological, and methodological history of geography and, specifically, health geography. The focus on health geography reflects the unique methodological influences which shaped the sub-disciplines and led to the cultural turn in human geography. Drawing on the history of the sub-discipline, this chapter examines whether there is a ‘place’ for participatory research within health geography.

Chapter Four: Social Capital Theory and Participation in Civil Society

Community-based participatory research draws from the resources we find in our social networks to work toward a process of social action. The research approach is fundamentally a social process leading me to draw heavily from social capital theory to understand what factors need to be present in a ‘community’ to facilitate the adoption of participatory research approaches. This chapter details the origins of social capital theory, the often conflicting views of the dominant theorists, and seeks to understand its importance in facilitating the everyday activities of civil society.

Chapter Five: The Limits of Community

Chapter Five builds on the concept of social capital introduced in Chapter Four to understand how social relations shape society and thus our efforts to work toward social change. In this chapter, I examine what is meant by the term ‘community’ and how social experiences such as stigma and ethnic diversity influence social cohesion. In Chapter Five, I also discuss the geographic literature connecting social capital with health and place as a grounding for understanding how the concept may be furthered within health geography research. Finally, CBPR is discussed in its broader political context, particularly its success as a tool for social engineering with the potential to create social capital on a large scale.

Chapter Six: Study Methods & Implementation

Chapter Six revisits the process of implementing participatory research by re-examining the goals of the thesis and the means by which they will be achieved. The methods adopted within the study are discussed, specifically, participant observation, interviews, and surveys, and the justification for the use of these approaches is provided.

Chapter Seven: The Case Study Context

This chapter introduces the three case studies which inform the thesis and describes the nature of the city within which the study is located. The characteristics of the population and the research background relevant to each of the case studies is discussed briefly providing a basis through which the results of the case studies may be better understood. The final section in this chapter examines the organizational contexts of the case studies and reflects on how external organizations may be facilitators or barriers to the research process.

Chapter Eight: Community Organizing & the Implementation of Community-Based Participatory Research

Building on Chapter Seven this chapter examines how social experiences such as stigma and social diversity impact on the implementation of community-based participatory research. In this chapter, I draw from the very different case study experiences of working with people living with HIV/AIDS and with those living in social housing settings. I examine what social processes contribute to the achievement of participation and discuss the strategies participatory researchers may employ to enhance the likelihood of success with the research strategy.

Chapter Nine: The Process of Community-Based Participatory Research

The process of implementing CBPR is discussed in Chapter Nine. Drawing primarily from participant observation in this chapter, I discuss the challenges to achieving meaningful participation throughout the research process making connections with existing literature. This chapter documents how social capital contributes to the success of participatory research, but equally, how a lack of momentum can threaten its sustenance.

Chapter Ten: Outcomes of the Community-Based Participatory Research Process

The final results chapter, entitled ‘Outcomes of the Community-Based Participatory Research Process’, draws on the voices of the research stakeholders to reflect on the research process and examine the value of the approach to those involved. I draw primarily from interview material to discuss whether the stakeholders see any transformative process of ‘conscientization’ took place through the research process and the value of any knowledge gained. Finally, the cost to the stakeholders in terms of time and energy invested in the project are weighed up against the positive outcomes they experienced.

The concluding chapter, Chapter Eleven, seeks to draw the theoretical and practical experiences of CBPR together to gain a better understanding of how effective processes for achieving social change may be and the circumstances under which they are best implemented. The thesis concludes with a critical reflection on the paradoxes inherent to CBPR and its potential as a research tool for health geographers.

1.5 SUMMARY

Through this thesis I seek to gain an understanding of the effectiveness of CBPR as a strategy for gaining knowledge, empowering communities, and achieving greater equality in the research process. While participatory research strategies have been gaining in popularity, CBPR has been largely overlooked by geographers and particularly health geographers. Through the implementation and evaluation of three CBPR case studies I reflect on the challenges to achieving collaborative community-based research and whether the benefits of the approach outweigh the difficulties.

Throughout this thesis, I draw heavily on the concept of social capital and related understandings of social diversity as factors which influence our understanding of 'communities.' This larger-scale perspective works with the case studies to provide an understanding of CBPR as a tool for social engineering which may not provide the positive results to justify its implementation.

Chapter Two

The Principles of Community-Based Participatory Research

> In the past few decades, a new paradigm of 'participatory' research has emerged, raising challenges to the positivist view of science, the construction and use of knowledge; the role of the researcher in engaging society, the role of agency and participation of the community, and the importance of power relations that permeate the research process and our capacity to become a just and more equitable society.
>
> (Wallerstein & Duran, 2003:27)

Community participation is not a new concept for research; it has been around for decades in agricultural systems science and has been gaining in popularity within the health sciences in recent years. Community-based participatory research (CPBR) is an approach in which tangible research outcomes are being worked toward while the social process of carrying out research transforms communities. Community engagement and empowerment occupy key goals in the participatory research process. This re-prioritizing of values has important implications for the kinds of questions we ask as researchers, the methods we adopt to investigate our research questions, and the means through which we disseminate our results as we must incorporate not just community participation but education and genuine engagement in all stages of the research. Discussions within this chapter will contribute to a theory of how participatory research may systematically enrich the communities involved and thereby contribute to the vitality of a given place. The principles governing the development of CBPR and the ideals which underpin its implementation are also discussed within this chapter.

2.1 THE BACKGROUND TO PARTICIPATORY RESEARCH

> Bourdieu reminds us that neither communication nor sustained social interaction between a set of individuals sharing the same life conditions are sufficient to generate a social collectivity, much less a mobilized one.... Indeed without wanting to minimize the significance of technical constraints, it must be emphasized that between interests and collective actions there exists a chasm that can only be bridged by an immense amount of labor – a labor that is carried out, above all, in the symbolic register. The actors who organize and mobilize on behalf of 'their' class must first recognize themselves as members of the same social collectivity with the same interests and the same adversaries.
>
> (Weininger, 2005:114)

Participatory research approaches were first implemented in developing countries with the purpose of overcoming local cynicism toward western development initiatives (Green and Mercer, 2001). Despite being grounded in moral ideals of empowering marginalized peoples, participatory research was more a reaction by academics to growing resistance amongst over-researched communities than a genuine attempt to improve the ethics of research. In developed countries, the rise of participatory approaches followed a similar trajectory as indigenous peoples began to resist the implementation of research where they received only minimal direct benefits from participating, often not even receiving study results.[5]

Participatory research has been rapidly gaining in popularity since the 1980s with its application no longer limited in purpose to appeasing research resistant populations. Much of the popularity came about as researchers faced increasing criticism for employing paternalistic approaches in which participants are treated as subjects for

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[5] "Native American and Canadian First Nations communities, for example, after decades of serving as subjects for anthropologic and epidemiologic studies, behavioural surveys, and health education program evaluations, have put the brakes on external researchers' exploiting their circumstances while providing very little benefit to their communities (Green & Mercer, 2001:1926)."

scrutiny, rather than valued for their knowledge. The qualitative turn of the social sciences in the 1970s saw researchers re-examine the goals of their research and acknowledge the limitations of the positivist approach they had adopted in the past (De Oliveira and de Oliveira, 1982; Institute for Health Promotion Research, 1995). The decline of positivist research methods was stimulated by the rise of a number of critical perspectives interested in addressing the inequalities experienced by marginalised groups in society such as women and ethnic minorities. In many respects, the premises on which participatory research was founded, specifically questioning the power relations within research and the reductionist approaches of positivist methods, are common across many of the qualitatively driven research paradigms, including feminism and postmodernism (Maguire, 1987). Like feminists and postmodernists, those embracing participatory research were uncomfortable with the potentially exploitative relationship between researcher and subject and sought an approach to reduce the power imbalance which favours the researcher.

2.1.1 Toward a Participatory Research Paradigm

In the early years of participatory research, there was confusion surrounding whether participatory research was actually a method in its own right or a methodology (Cornwall and Jewkes, 1995; Institute of Health Promotion Research, 1995). A methodology is commonly defined as the study of practices and rules governing a system of inquiry and involves reflecting on the appropriateness of the adoption of particular methods (Potter, 1989). The method of inquiry is equated with the data gathering tools, whether they be interviews, focus groups, etc. Early discussions of participatory research advocated the need to use qualitative methods to achieve participatory research goals (see, for example, Hall et al., 1982); a claim countered by authors such as Baum (1995) who argue the approach should not be restricted to particular methods: “What is distinctive about participatory research is not the methods, but the methodological contexts of their application. Similar methods can be used quite differently according to the choice methodological researchers make, which in turn is influenced as much by their attitudes as by their training” (Baum (1995) as cited in Cornwall and Jewke, 1995:1667).

Participatory research is conceived of as a methodology by Cornwall and Jewkes (1995) who parallel the principles governing participatory research (specifically the ‘reflexive, flexible and iterative’ methodologies) with those of grounded theory, a widely accepted methodology founded upon the importance of emergent ideas (Strauss 1990). Cornwall and Jewkes (1998:1671) even go so far as to assert that “PR [Participatory Research]/PAR [Participatory Action Research] is more of an attitude or approach than a series of techniques.” Participatory research can be applied in the context of any method and diverges from prominent qualitative methodologies in its radical approach to questioning existing social structures and devolving of power to communities. In this sense, participatory research does not fit the criteria of a methodology as its key defining features are: (a) intensive collaboration between the researcher and community, (b) a reciprocal education process between the two parties, and (c) a commitment to acting on the issue at hand (Institute of Health Promotion Research 1995:3). Common to these factors is an emphasis on the practices surrounding research and a reinterpretation of who is eligible to carry out research. There is little emphasis on the way in which research strategies should be employed as we would expect from a methodology.

Participatory research may more accurately be conceived of in terms of an epistemology. Baum (1995) is careful to stress that while the methodology and epistemology should be compatible the two are not synonymous. Potter (1989:234) defines an epistemology to be: “Theories of what knowledge is, what it is possible to have knowledge of, how it is possible to have knowledge at all etc.” The participatory research perspective supports the notion that all individuals in society possess knowledge and are capable of contributing to its production. In this way, the participatory approach determines how we gain knowledge but falls short of providing a cohesive theory detailing what knowledge is. Participatory approaches provide us with what may be best described as a new research paradigm, that is, a new perspective on “the working assumptions, procedures and findings routinely accepted by a group of scholars, which together define a stable pattern of scientific activity” (Johnston et al., 1994:432). The concept of paradigms has met with little success when applied in the Kuhnian sense to human geography and there is little evidence that a paradigm shift in its grandest sense is inevitable within the discipline (Johnston et al., 1994:432). If we, however, conceive of paradigms in human geography as multiple (for example, feminist, Marxist, and positivist paradigms) then they may coexist and even strengthen each other through the processes of debate and questioning. It is this ‘messy’ context of social science research which no doubt led Kuhn to limit his theoretical applications to the natural sciences.

A participatory research paradigm would be founded on a belief that academics play a central role in upholding the knowledge hierarchy of society by occupying positions of authority regarding what constitutes valid, that is scientific, knowledge. A participatory paradigm challenges common assumptions that only academics and others who are professionally trained have the authority to determine what constitutes knowledge; instead knowledge is seen as an instrument through which power is distributed. Under a participatory paradigm knowledge is possessed by those whose lives are affected by the research problem at hand and the role of academics is to work with community members to allow their knowledge to occupy a space of authority alongside academic knowledge.

Participatory researchers advocate for the formation of partnerships between researchers and community members thereby enhancing the control and ownership communities have over research into issues which concern them. In this way, research emerges which more accurately represents the social realities of participants (Hall et al., 1982). Freire (1970) believes that liberation from the existing social order must begin with the oppressed and those who sympathise with the cause, as these are the people that truly understand why liberation is necessary. Participatory research is one tool which is used to transform inequalities in society: "It assists organized activities of ordinary people who have little power and small means to come together and change the structural features of their social milieu in an effort to realize a fuller life and a more just society." (Park, 1993:2) Participatory research is inherently educational in nature, working to empower individuals and communities to develop a more critical consciousness, in which one's place in the world may be questioned and determination over one's life (re)claimed (Freire, 1970; Park, 1993). Some level of education occurs in all research. Where participatory research differs from traditional research approaches is in facilitating learning on the part of both the researcher and the participants. Coming from an educational background, Freire (1970) suggests that it is in transforming one's consciousness in order to become critical of the structures of oppression in society that the educator's (or facilitator's) role becomes important.

2.1.2 The Origins & Definition of Participatory Research

Participatory research is also referred to as 'action research', 'community based participatory research', 'cooperative inquiry' and other derivations of these terms, with subtle differences present among the labels. 'Action research' legitimizes praxis as an avenue for knowledge creation and pioneered research driven by the need to find a practical solution to a real-life problem (Maguire, 1987). Action research tends to be organization focussed with a lesser emphasis on collaboration between the researcher and participant than is present within participatory research (Tandon, 1996).

The term ‘community based participatory research’ (CBPR) refers to the form of research applied within this study and emphasises collaboration with the public as the focus of the approach. Attempts to define exactly what CBPR is have been highly debated due to the subjective nature of the term ‘community’ and the multiple levels at which ‘participation’ in research may take place. Earlier understandings of ‘community’ were based on a defined geographic area and assumed a level of homogeneity amongst people residing within a region (Woelk, 1982). More recently, ‘community’ has been broadened to refer to a group sharing common characteristics which, in turn, makes them different from others in society (Cohen, 1985 in Vingilis, 2003). ‘Community’ is a socially constructed notion, implying a sense of identity amongst those with whom a commonality is shared (Israel, 2003). This sense of ‘sharing’ common qualities, according to Labonte (1997:10): “is not some demographic datum, it is the dynamic act of people being together.” In my research, the understanding of ‘community’ is applied to population groups relevant to the three case studies, specifically, people living with HIV/AIDS in the study region, people living with disabilities in the study region, or residents of selected social housing complexes where there was a clear spatial demarcation of the ‘community.’ The nature of ‘community’ and its relevance to the diversity of experiences and perspectives of stakeholders is an issue which is addressed in the later chapters of the thesis.

Mode of Participation	Involvement of Local People	Relationship of Research and Action to Local People
Cooption	Token; representatives are chosen, but no real input or power	On
Compliance	Tasks are assigned, with incentives; outsiders decide agenda and direct the process	For
Consultation	Local opinions asked, outsiders analyse and decide on a course of action	For / with
Cooperation	Local people work together with outsiders to determine priorities, responsibility remains with outsiders for directing the process	With
Co-learning	Local people and outsiders share their knowledge, to create new understanding, and work together to form action plans, with outsider facilitation.	With / by
Collective Action	Local people set their own agenda and mobilized to carry it out in the absence of outside initiators and facilitators	By

Table 2.1: Participatory Methods: Means to what ends?
Source: Cornwall (1996:96).

Defining ‘community participation’ in research is also problematic due to the multiple understandings of ‘participatory’ leading community involvement taking on many different levels across research projects. Table 2.1 depicts the range of levels at which participation in research may occur. At the most basic level participation is focused within the data collection stage of a study as the researcher ‘empowers’ participants by conducting interviews (or other methods of data collection) in which participants are seen not as research subjects but rather as providers of knowledge (Kesby, 2004). In this instance, community members have little say over the direction of the research and the researcher will return to her/his institution and may choose simply to continue community activism as an academic commentator. ‘Compliance’ occurs when the research is designed by outsiders and community members are recruited to carry out particular tasks, such as interviews. The research questions still originate with the outside researchers. Cornwall (1996) defines research where community members provide input into the research problem as being carried out at the 'consultation' level. In this instance researchers are acting on the knowledge of the community members but are still working relatively autonomously by interpreting the realities of the community and making decisions themselves. It is at this level of participation and beyond that CBPR takes place.

At the cooperation level of participation, decisions are jointly made with the community members and outside researchers but ultimately the outsiders provide the timeline and other imperatives for completing the process. The strategy the present research aims for is that of co-learning, in which community members work with outside researchers to determine a study focus, develop action plans and contribute to new knowledge. This approach values community members as potential researchers who, by gaining tools and experience, may be equipped to carry out research at the collective action level in the future and therefore achieve social change independently.

Finally, at the most participatory end of the spectrum, collective action entails the community making research decisions independent of outside facilitators. Community members may, however, choose to employ outside researchers as consultants to address the tasks they define.

A number of authors warn of the impossibility of achieving 'purist' participatory research, equivalent to the collective action level of participation identified in Table 2.1 (DeKonig and Martin, 1996; Maguire, 1987). A purist approach would see a community initiate the research process and seek the support of researchers rather than the researchers pursuing the community. In reality, this organic approach to participatory research is rare particularly amongst the most marginalized groups where self-determination at the collective level may be limited. Maguire (1987), for example, found herself forced into a state of inaction as she awaited the ideal circumstances for participatory research to develop with the group of abused women with whom she was working. Eventually Maguire (1987) did take action to instigate the participatory research process with the group signalling the importance of the facilitator role of the researcher.

2.1.3 Empowerment

Empowerment is fundamental to the ideology governing both CBPR and health promotion practice. Empowerment is seen as part of a more holistic understanding of health adopted widely in health promotion; health promotion, therefore, involves a process of “community ownership and control of their own endeavours and destinies” (Ottawa Charter for Health Promotion, 1986:331). Likewise, drawing from a number of sources Kar et al., (1999:1433) define empowerment to be “a process through which individuals, communities and organizations gain control over issues and problems that concern them most.” While research is the primary strategy for empowerment in CBPR multiple other means of empowerment exist and may include demonstrations, mutual support, the formation of unions, public education, storytelling, involvement in political campaigns, petitions, marches, or the pursuit of legal avenues for justice (Kar et al., 1999; Williams et al., 2003).

The process of empowerment is presently poorly understood; perhaps one of the few issues which are widely agreed upon when it comes to participatory research and empowerment is that it *is* a process (Speer et al., 2001). Empowerment is believed to be enhanced by the pursuit of social action, the leadership of individuals, and social context (Kar et al., 1999). Empowerment can be understood as consisting of a number of different dimensions, broken into intrapersonal factors (one's perceptions of oneself), interactional (how one relates to others and the environment particularly, in terms of leadership and "knowledge of the resources required and methods to access those resources to produce social change), and behavioural (in effect the ability to enact positive change)" (Speer et al., 2001:717).

The work by Speer et al., (2001) is significant for the population level connections made between social cohesion, participation and empowerment. The authors found those individuals who participate *independently* in civic life (for example through letter writing) have greater levels of individual empowerment yet are less likely to have a high sense of community than their peers who participate *socially* in civic life (Speer et al., 2001). Importantly for this research Speer et al., (2001:727) indicate that "participation may be more important than sense of community for intrapersonal empowerment, while sense of community may be more important than participation for interactional empowerment." Given that CBPR aims to achieve participation at both the individual and community levels the process of fostering social cohesion may turn out to be just as important as the skills learned through the research process. This finding differs somewhat from the emphasis most discussions of participatory research place on the community group taking control of the research process.

Participatory research literature emphasises the positive role of the researcher and their need to step back from a leadership role into a facilitator role in order for the empowerment process to be meaningful (Tengland, 2006). The process of empowerment, however, is not this one-dimensional, as we witness those communities in which a high level of empowerment has already been reached taking a more significant role in shaping research. Likewise, those community members more familiar with research and aware of the benefits it may afford them tend to be involved in participatory research projects in more meaningful ways. Instances of co-learning, for example, are most often carried out with individuals in positions of relative power such as staff of health care organizations and members of local community groups. While the community is benefiting from the outcomes of this collaboration the knowledge and skills of only a few who are already in privileged positions are being enhanced. These approaches to participatory research have enjoyed relative success likely due to the stake the community members already have in the research at hand, their commitment to addressing the needs of their community and the relative level of familiarity they have with thinking conceptually around how to better meet community needs.

2.1.4 Scale

The scale at which participatory research is carried out tends to be influenced by the participatory approach being worked toward. Examples of larger-scale participatory research are more likely to include skilled community members in projects that are wide-reaching (see Fenton et al., 2002; Giachello et al., 2003; Morisky et al., 2004), in other words, the greater the number of people involved, the more significant the research goals are likely to be and it will impact larger spatial areas. These projects also tend to involve prescribed research goals implemented in a top-down manner through strategies such as the employment of community interviewers. Projects involving purely lay community members, on the other hand, tend to be smaller in scale involving fewer community members and with more modest goals (e.g., see Low et al., 2000; Maguire, 1987). There is also greater opportunity for community members to take a significant role in the decision making as fewer organizations (such as funders) will be restraining the process.

The scale at which the project is implemented also has clear implications for its long-term sustainability. The maintenance of a group is hindered by small closed social networks, particularly in instances where members have high rates of turnover, and this may be typical of a small-scale participatory research project. Large-scale projects, in contrast, often involve community organizations where the stability of paid positions is complemented by the institutional memory which may be upheld even when one person leaves the project. In this respect, larger-scale projects tend to have stronger formal networks through which relationships are maintained. It is unclear whether this trend is purely a function of the skill level of the engaged community members or whether project funding also plays a role. There has been extensive discussion of the limiting effect sourcing revenue from traditional research funding agencies can have on participatory research activities with researchers discussing the reluctance of funders to invest in a project where the goals have yet to be determined, or they simply do not understand the imperative behind engaging community members as active researchers alongside the 'experts' (Naylor et al., 2002).

2.1.5 Values of Participatory Research

Community-based participatory research is founded on a number of values. Amongst the most important is the assumption that the more collaborative the project the greater the opportunity is for community learning. CBPR at the co-learning level seeks to position community members as holders of power throughout the research process, competent of making the pivotal decisions regarding the focus of the research and their roles in carrying it out. The researcher’s task is to work with community members to ensure that they have access to the knowledge, skills, and resources in order to succeed in their project. To optimize learning through the participatory process Hall (1998) sees the need for researchers to use their power to strive toward assigning as much of it back to the community as possible.[6] In working toward a high level of participation in research, Hall (1998) suggests that the researcher be mindful of the following philosophical ideals when engaging the community in the research process:

> The community should gain the tools with which to better instigate problem solving through their participation in the research process.
>
> A research process should involve the community in the entire research project, from the formulation of the problem and the interpretation of the findings to planning corrective action based upon them.
>
> The research process should be seen as part of a total educational experience which serves to determine community needs, and to increase awareness of problems and commitment to solutions within the community.
>
> Research should be viewed as a dialectic process, a dialogue over time, and not as a static picture of reality at one point in time.
>
> The object of research, like the object of education should be the liberation of human creative potential and the mobilization of human resources for the solution of social problems.
>
> Research has ideological implications.
>
> (Hall, 1998:221-4)

Hall’s (1998) research process considers participation to be an educational process, sufficiently intense that ideals of social cooperation and skills of community organising may be adopted by community members. Participatory epistemologies override assumptions that to carry out research one must have the appropriate academic qualifications and institutional affiliations. Rather, the process requires a level of

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[6] This is an approach rejected by Bourdieu, who sees the value of academics to be in their autonomy as ‘scientists’; Bourdieu argues that we can further the political through the scientific – though he does not address the inherent power imbalance that this approach reproduces (Bourdieu and Wacquant, 1984, as cited in Wilton, 2004:120).

commitment on behalf of both the academic researcher and the community to a process which may or may not achieve the desired research goals or expectations of positive community change.

2.2 PARTICIPATORY RESEARCH, SOCIAL CHANGE, FREIRE, & BOURDIEU

The first stage of CBPR is to work with communities to identify systematic inequalities which contribute to their marginalization and later to challenge these inequalities. Paulo Freire (1970) is credited with establishing this theoretical basis of participatory research. As an educator focussing on literacy in Latin America, Freire was extremely critical of the power structures which lead groups in society to become caught in a state of oppression. Freire (1970, 1970a) felt that marginalized communities need to understand their position as located within the broader framework of oppression if they are to challenge successfully their situation in society.

Freire’s views were formed during a politically and economically vulnerable period in Latin American history captured in van Gorder’s (2007:11) interpretation of Freire’s outlook: “All educational structures and theories, according to Freire, begin within specific political frameworks.” Freire was born into poverty in Brazil and chose to work with those in the most abject poverty because of their increased capacity to comprehend the systemic sources of oppression (Choules, 2007). Freire’s work was focussed in the northeast of Brazil, a region experiencing in the 1950s the greatest poverty in Latin America and widespread illiteracy (Kirkendall, 2004). At this time literacy was a major focus of the region; Cuba’s success in reducing illiteracy served as impetus for the US to invest in raising literacy throughout the Americas (Kirkendall, 2004). Aware of the political impact of knowledge, Freire’s revolution was built on education: “Teaching, he believed, can never be divorced from the critical analysis of how society works, and teachers must challenge learners to think critically about the social, political, and historical realities within which they inhabit the world" (Jackson, 2007:203). Freire's method of pairing political awakening with literacy education met with great success (Kirkendall, 2004).

The politically driven nature of Freire's means of enhancing literacy made him a target of right wing politicians who recognized the potential threat of awakening the political and educational potential amongst those who had been excluded from voting on the basis of their illiteracy (Kirikendall, 2004). Funding for Freire's work was withdrawn with the explanation of administrative inadequacies; later in the 1960s, Freire was arrested during a military coup in Brazil in which many programme members were targeted; he was forced to flee the country, later settling in Chile. Freire's success in Brazil as a political awakener remains a point of contention as those ardent supporters of his work are countered by the defeats he faced; Kirkendally (2004:185) cites Ibare Dantas (1967) to argue that "the triumphalist rhetoric of many of the left [such as Freire] blinded them to the fact that the powers of reaction, and the military, in particular (which, for its part, claimed to have its own revolutionary agenda) were much stronger than the divided left was."

Freire is known foremost as an educator and this is why his theorizing of the inclusion of lay persons as researchers viewing critically their own realities has been so influential. Freire (1970) is against the "culture of silence" which pervades society, oppressing and further distinguishing those without a voice from their oppressors who have a voice. In his conceptualisation of society, Freire (1970) creates a binary of power polarizing the oppressed from their oppressors who, he argues, steal the humanity of the oppressed but in doing so lose their own humanity through their oppressing actions. There are substantial problems with Freire’s conceptualisation of ‘the oppressed’ as a unified group consistent in their need for emancipation and critical awareness. While this characterization of a uniformly oppressed portion of society may be seen to facilitate the achievement of political goals, in the same way the characterisation of women as uniformly dominated was argued as necessary for women’s empowerment, we risk overlooking differences amongst ‘oppressed’ groups brought about by such factors as health status and ethnicity (Gibson-Graham, 1994).

Standing in the way of universal characterizations, argues Gibson-Graham (1994:214) is the lack of transcending identity from which social and political change may be fostered; yet we do see “existing discourses that position subjects in relations of empowerment and disempowerment. The ways in which theory and research interact with these discourses have concrete political effects.” The theory of oppression developed by Freire (1970) explicitly positions the oppressed as a distinct societal group in need of emancipation from what is depicted as both a discourse and reality of domination. In this respect the theory of oppression is critical to the achievement of the form of social and political change identified by Freire. Freire (1970) believes the oppressed predominantly function at a level of semi-intransitive consciousness in which one’s challenges are perceived as outside of one’s own control, often resulting in the adoption of a fatalistic attitude in which those in power are seen to be responsible for creating the situation. It is in achieving a level of critical consciousness – incorporating what Freire terms a ‘structural perception’ – that we recognise the impact social structures have on one’s position in society (De Konig and Martin, 1996; Freire, 1970). It is the task of the oppressed then to liberate both themselves and their oppressors from the process of dehumanization caused by this power imbalance:

> Critical investigation helps people to look at problems about the reality surrounding them in the light of what they wish to achieve as self-reliant and self-determining social beings. Research, in this case, has to do with questions concerning the life chances we are entitled to as members of a society, as well as with the comprehension of the social obstacles standing more immediately in the way of achieving these goals.
>
> (Park, 1993:7)

Freire (1970) believes the process of challenging the position of the oppressed in participatory research begins with the researcher who instigates the conscientization process. This raises the question of how important the agency, or self-determination, of individuals is to achieving social change: "The term agency is linked with the recognition that people have a degree of independence in their daily lives, and may change the course of events" (Harrison and Davis, 2001:6). It becomes clear that either the oppressed have no agency or, as Freire (1970) argues, agency was stolen through a process of dehumanization. The implication for the researcher, regardless of whether she or he subscribes to the concept of agency, is to challenge what Freire (1970a:31) alludes to as the presence of systematic, or prescribed, ways of thinking: "Every prescription represents the imposition of one man's [sic] choice upon another, transforming the consciousness of the man prescribed to into one that conforms with the prescriber's consciousness. Thus, the behavior of the oppressed is a prescribed behaviour, following as it does the guidelines of the oppressor." This shared consciousness reinforces the symbiotic relationship between the oppressors and oppressed in society, preventing the oppressed from challenging their situation. The researcher plays a key role in facilitating the critical awareness of stakeholders through the CBPR process. The emphasis Freire places on his concept of 'conscientization' is, however, lessened in his later work where he goes back to the importance of literacy and the written word as a tool for transformation.

Critics of Freire look to the lack of tangible change effected by individual action within his framework. The potential Freire provides for active citizenship by the individual is limited largely to the actions of the researcher with the individual opposed largely absent; Freire's conceptualisation is geared toward the possibility of social change should transformation of the 'masses' prove successful. The effectiveness of the approach at the individual level is one element this research aims to assess.

2.2.1 Bourdieu & Social Space

Bourdieu's (1998) habitus shares much in common with Freire's conceptualisation of oppression. The 'oppressed' are confined to function within a frame of reference defined by forces from the broader society, linking their consciousness to that of their oppressors. Within Bourdieu's (1998) social space are networks of 'fields' whose structuring effects are felt through social processes like rules, regulations, rituals, and rights, which shape one's social reality. Each field (occupation, political party etc.) has a spectrum of alternatives from which individual choice allows for the production of identity in what Bourdieu (1984:226) terms "the pursuit of distinction". The field thus orients one toward particular dispositions and practices as "each social field has a profile of its own, depending on the proportionate importance within it of each of the forms of capital" (Siisiäinen 2000:no page). But the field is also a site of contestation as individuals compete for authority (e.g. by illustrating high levels of cultural capital in the art arena through their knowledge of impressionism) (Wacquant 1987).

The social field is the 'anchoring' for one's habitus serving to demarcate differences in society by rendering one's 'social subjectivity' (McLeod, 2005). "The habitus, according to Bourdieu, is differentially formed according to each actor's position in social space; as such, it is empirically variable and class specific (in Bourdieu's sense of the term)" (Weinnger 2005:91). One's behaviours are shaped by the 'subjective structures' of the habitus which predispose a person to certain alternatives when making choices (Bourdieu 1977 as cited in Siisiäinen, 2000). Bourdieu (1998) appears to see one's habitus as a self-determining cycle (e.g., one's position defines the goods that one consumes and thus serves further to cement one's position in society). The habitus, rather than being fixed, evolves with new experiences by reinforcing existing dispositions, or by triggering change thus modifying the habitus. The habitus allows us to distinguish ourselves from others in society who share different political beliefs, economic circumstances, and cultural status and to reinforce the appropriateness of one's choices and behaviour. "Practice – everyday activities – is therefore shaped both by the habitus, which disposes people to act in particular ways, and by the availability of various types of capital in different fields" (Gatrell et al., 2004:248). In this sense, social capital may not be accessed without the individual's predisposition to rely on social connections as a resource and, we could hypothesize, these predispositions are likely to influence significantly the successful development of participatory research processes.[7]

Through Bourdieu's (1984) understanding of the interrelations between habitus and the field we gain insight into the reciprocal relationship between the shaping of individual and societal consciousness. This runs in contrast to structuralism where there is a risk that the constraints impacting individuals may appear spontaneous. Bourdieu (1984) identifies a source of oppression in everyday social interactions which we can tangibly work to address by identifying and challenging the dominant power structures. Bourdieu

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[7] The work of Bourdieu (1988) has been a growing focus of geographers, such as Gatrell (2004) who have become aware of the significant implications of Bourdieu's work for our understanding of how human influence is affected by space. See Chapter Five for further details.

(1984) argues that one's social position is an ongoing production of the class habitus that one occupies and in this sense class is a production of social space reliant on social groups subscribing to and aligning themselves with the concept (Weinnger 2005). In this way, dominant and subordinate groups emerge and distinguish their relative levels of material and symbolic capital through their actions, possessions, and life decisions (Weinnger 2005): "...the social order is progressively inscribed in people's minds. Objective limits become a sense of limits, a practical anticipation of objective limits acquired by experience of objective limits, a 'sense of one's place' which leads one to exclude oneself from the goods, persons, places and so forth from which one is excluded" (Bourdieu, 1984:470-1).

2.3 CBPR AS A DYNAMIC, REFLEXIVE PROCESS FOR CHANGE

Participatory approaches differ from positivist paradigms in a number of ways; however; it is the devolving of power to the community which stands most starkly in opposition to the positivist ideals of research. Not only are researchers deemed value-laden in participatory research, but those conducting the research – the community – are not 'qualified' to carry out the research; they are emotionally involved in their research topic and are politically motivated. How then can research of 'value' (i.e., objective and impartial) be produced when those conducting the research are motivated by the achievement of political ends?

Maguire (1987:35) asserts that "there is a political nature to all we do; all of our work has implications for the distribution of power in society. Given this assumption, there can be no neutral or value-free social science." What Maguire is arguing is that the production of research is merely another venue in which power is contested. All researchers are driven to meet their own political ends, whether they are academics wanting publishable results, or participants wishing to expose inequalities within their environment. The values and ‘biases’ of the community may even double as goals of the participatory research project as the process works toward identifying and addressing issues of concern to the participant.

> Some may think it inadvisable to include the people as investigators in the search for their own meaningful thematics: that their intrusive influence (N.B. the ‘intrusion’ of those who are most interested – or ought to be – in their own education) will ‘adulterate’ the findings and thereby sacrifice the objectivity of the investigation. This view mistakenly presupposes that themes exist, in their original objective purity, outside men [sic] – as if themes were things. Actually, themes exist in men [sic] in their relations with the world, with reference to concrete facts.... There is, therefore, a relation between the given objective fact, the perception men have of this fact and the generative themes.
>
> (Freire, 1970a:97-8)

The difference between the subjectivity of the researcher and that of the community is in the explicit nature of the perspective that the community brings to the project. Freire (1970a:35) argues that “one cannot conceive of objectivity without subjectivity” that one must exist in a “constant dialectical relationship”, with the implication for research being an acknowledgement that the researcher brings his or her own form of subjectivity into the research process and the feminist notions of positionality and reflexivity become integral to the research process. Reason (1994:11) argues that the participatory movement involves the development of a world-view which “will move towards forms of knowing that are self-reflexive, that are both deeply engaged and rigorously self-critical.” While Reason (1994) does not expand on how this self-reflexivity should be employed I see the practice as a means by which the perspectives and experiences of the outside researchers and community members may be articulated allowing for the context of the research results to be better understood. In this respect the academic researcher must urge stakeholders at key steps of the research process to reflect on their views and attitudes and how these are impacting on the research; when the reader is aware of the perspective a researcher brings to his/her work they are better able to evaluate the research results and overcome any biases which may otherwise be hidden.

While feminists and other social researchers have become increasingly self-reflexive over recent years questions remain as to whether reflexivity is enough (Kobayashi, 2003), leading, to debates regarding who is ‘entitled’ to carry out research with more marginalized societal groups (Valentine, 2002). Yet taken for granted in these debates is the importance of political positionality, whether it is stating one’s feminist beliefs or situating oneself as believing in the need for change in a given area. The process of positioning oneself in relation to one’s research need not be extensive and overly personal, rather, a reflection on the viewpoints one brings into the research and one’s level of distance from the problem at hand may be sufficient.

2.3.1 Social Action through Participatory Research

“The purpose of participatory research is not merely to describe and interpret social reality but to radically change it. Furthermore, the intent is to transform reality ‘with’ rather than ‘for’ oppressed people” explains Maguire (1987:28). Participatory research differs significantly from traditional research in that the results phase does not signal the end of the process. Participatory research aims to make real changes to the community under investigation through practical action which draws from the results of the research. Through action the links between the structural limitations in one’s environment and the potential to challenge those limitations becomes evident. We may not overcome the oppression in society, but we can challenge it, and this lesson in challenging existing power structures may arguably be most significant for all involved in the participatory process. The results of participatory research provide direction and evidence to move forward with action to counter the oppression evident within the collaborating community: “Most important, the assembled findings of the investigation serve as topics of collective reflection achieved through dialogue. The products of participatory research not only provide people with the technical ammunition for improving their material conditions and for engaging in political struggles, but also supply the grist for their reflection mill.” (Park, 1993:15) In this way, we see real, tangible, benefits which extend beyond meeting the needs of the researcher to improving conditions of the community as a whole.

Participatory research works toward a level of critical consciousness amongst participants that triggers social action to achieve material change. Park (1993:8) explains that as community members become aware that their place in society is a function of long established human action strategies for change “critique thus turns into will to action and action itself.” We then see a circular process emerge where communities learn from their actions and continue to work to raise consciousness and challenge their place in society. This form of self-reflection is what Freire (1970a) is referring to when he talks of conscientization.

2.3.2 Freire, Bourdieu, & Geographic Research

Collectively Freire (1970) and Bourdieu (1988) provide an understanding of power as a function of the social relations within society. Bourdieu (1988) depicts social structures as spatial, grounded in the social and geographic distance between social groups; his work having important implications for human geographers as he examines the relative importance of geographic space as a force of social difference. Bourdieu (1988) argues that even when geographical distance is bridged between two socio-culturally polarized individuals the social differences between them will work against the development of a relationship. Specifically, the language the two individuals use, their manners, and their symbolic registers will be opposed. In contrast: “proximity in social space predisposes to closer relations: people who are inscribed in a restricted sector of the space will be both closer (in their properties and in their dispositions, *their tastes*) and more disposed to get closer, as well as being easier to bring together, to mobilize” (Bourdieu, 1998:10-1).

Bourdieu’s (1988) work provides a framework upon which our understanding of social distinction may be based. When we consider Freire’s (1970) précis for overcoming oppression, the importance of the process of social distinction takes on new significance. Freire’s (1970) distinction between the oppressed and oppressors may be seen as the materialization of the focus of social, material, and cultural capital, creating what can only be described as marginalization across the social fields which become internalized. Freire (1970) proposes an educational and a research process for becoming aware of this marginalization and critical of the process which enforces it. Freire’s (1970) work poses a significant methodological and conceptual stretch to human geography as he requires academics adopt political roles as ‘liberators’ of human potential. These practices, which run counter to the academic mantra of publish or perish, require a long-term, involved commitment to the populations we study. In turn, this runs counter to the scientific ideals of neutrality in our research.

2.4 SUMMARY

Participatory research works toward breaking down the social structures which perpetuate inequalities in society and aims to facilitate community development at a number of levels. First, at the individual level, participants become empowered with the knowledge to view critically the presence of structures within their environment. Secondly, at the group level, community members become aware of their potential to use research as a tool to challenge structures when they bring their skills together. Thirdly and finally, at the community level, participatory research and subsequent research instigated action have the potential to challenge existing social structures and positively impact on the lives of those within the community. Participatory research allows both the researcher and participants to learn from each other and it empowers communities with the tools to continue to actualise change once the researcher is no longer involved, thus increasing the capacity of the community to address problems within their environment (Israel et al., 2003). To return to the words of Freire:

> ...participatory research is no enchanted magic wand that can be waved over the culture of silence, suddenly restoring the desperately needed voice that has been forbidden to rise and be heard... the silence is not a genetically or ontologically determined condition of these women and men but the expression of perverted social, economic and political structures which can be transformed. In the participatory research propounded here, the silenced are not just incidental to the curiosity of the researchers but are the masters of inquiry into the underlying causes of events in their world. In this context research becomes a means of moving them beyond silence into a quest to proclaim the world.
>
> (Freire 1993 as cited in Park et al., 1993)

Chapter Three

A Participatory Research Paradigm in the Context of Health Geography

The health geography literature is replete with commentaries on the changing focus of the sub-discipline as geographers have become more critical of biomedical perspectives and have sought more holistic approaches for researching health (Cummins and Milligan, 2000; Kearns and Moon, 2002; Parr, 1998; Rosenberg, 1998). Momentum for this shift has been drawn from social and, to a lesser extent, cultural geographies where movements such as feminism and poststructuralism have strongly influenced the kinds of questions researchers have been asking and the methods used to answer them.

The chapter begins by extending the discussion of research frameworks initiated in Chapter One to explore how the epistemological and methodological basis of medical geography has changed over time, leading to calls for new geographies of health. These changes within medical/health geography are viewed as an extension of the cultural turn within the parent discipline. Here, I seek to complement existing discussions of the dominant themes in health geography (Kearns and Moon, 1998; Rosenberg, 1998) with an explicit focus on their epistemological groundings to gain a better understanding of the impetus behind change in the sub-discipline. I conclude by considering how these epistemological developments have set the stage for a participatory paradigm to emerge.

3.1 EPISTEMOLOGIES OF MEDICAL GEOGRAPHY

Establishing a foundation of knowledge regarding what health geography is and how the sub-discipline has been shaped is necessary for gauging the need and appropriateness of a participatory research paradigm. Disciplinary developments, whether they be methodological or the identification of new research areas, are shaped by the research and knowledge traditions preceding them. I focus here on the concepts of epistemology, methodology, and research paradigm as these factors are most significant in shaping how we go about conducting research and what are seen to be legitimate foci of research

Epistemology is broadly defined as a theory of knowledge; epistemologies are a construction of what we accept knowledge to be and what valid sources of knowledge are and should be (Potter, 1999). A shift in the dominant epistemology sends ripple effects throughout all aspects of research practice as changes to our conceptions of what knowledge is and from where it may be sourced impact on which strategies are acceptable for data collection: “At the root the problem is epistemological: I have long believed, with Gregory Bateson, that the most important task before us is to learn to think in new ways (Bateson 1972), and thinking in new ways implies new forms of practice” (Reason, 1994:9). The cultural turn is an important example of this; as geographers become more interested in place as an experiential concept qualitative methods emerged as valid and arguably the bests way of knowing – calling into question notions of generalizability prominent throughout the rest of the (largely quantitative) discipline.

3.1.1 Empiricism & Positivism

Medical geography was founded on positivist traditions deriving epistemologically from empiricism, a perspective through which knowledge is understood to be objective, universal, and countable: “Knowledge is based on facts that are established by the orderly study of [sensed] objects” (Panelli, 2004:17). Empiricism is deeply entwined with positivism, both giving priority to knowledge derived from what can be observed and is, Darlaston-Jones (2007) argues, the site within which science is located thus serving to influence the language and methods adopted by scientists. Empiricism has come under fire from a number of sources, particularly postmodernists who argue that multiple competing perspectives may be valid sources of knowledge; postmodernism being a philosophy incompatible with the positivist search for universal truths. The problem of multiple competing perspectives is resolved within empiricism by the quest for ‘better’ measurement of the problem at hand and thus the invalidation of some sources of data. Applying ‘better’ science to increase the validity of results shapes empiricism and positivism as perspectives which reinforce the privilege awarded to scientists as producers of knowledge and distances research from the lay population.

Empiricism relies on expert structures, such as the peer review process, to vet the knowledge assertions of individuals and, in doing so, often excludes those outside of academia on the basis of a lack of familiarity with academic discourse or lack of access to the appropriate literature. This practice can be seen even within academia as many of the dominant Western journals exclude contributions from academic researchers in developing countries where up-to-date literature may be hard to come by or contemporary theory slow to gain popularity (Phillips and Rosenberg, 2000).

Empiricism has been a hugely influential epistemology extending across decades and disciplines to determine what constitutes ‘scientific’ knowledge: “The popular idea of science as final arbiter is so pervasive and strong that there is, nowadays, an institutionalized belief that without scientific proof of a relationship one has no basis for taking any decision (Bennett, 1991:340).” The problem that we have with ‘scientific’ knowledge, Bennett (1991) argues, is its failure to attain a level of ‘truth’ which transcends the need to employ processes of reasoning leading to repetition and randomization as tools to enhance the generalizability, and thus the ‘truth’, of knowledge. Out of positivism emerged a set of standards for determining what constitutes knowledge and how we may carry our research in a valid manner; these standards have been a focus for much discussion and criticism from social researchers who have engaged with the epistemological underpinnings of qualitative research and sought alternatives to positivism (Hughes, 1990).

Early discussions of medical geography commonly distinguish between two distinctive themes, disease ecology and health services research, which dominated the literature historically and remain important today (Kearns and Moon, 2002; Park et al., 1998). These themes draw strongly from empiricism, seeking data as the basis from which generalizable truths may be produced and viewing theory as an abstraction of the real world derived from the data collected.

3.1.2 Disease Ecology

Disease ecology emerges out of empiricist research epistemologies, sharing much in common with the medical research traditions of spatial epidemiology where compositional and contextual relationships between health and place are examined, often using geographical information systems (GIS) and advanced statistical modeling.[8] Disease ecology is concerned with such themes as the diffusion of disease throughout

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[8] This is in contrast to other streams of epidemiology where a preoccupation with causality sees much of this research founded in the epistemological grounding of realism.

society, analyzing the distribution of disease, and understanding the environmental causes of disease (Sui, 2007) and is seen as a means through which population level impacts on health, which are not evident at the individual level, may be detected (Curtis and Jones 1998).

The disease ecology stream of research remains vibrant in medical geography today, with researchers focussing particularly on relationships between neighbourhood characteristics and health (Curtis et al., 2006; Santos et al., 2006), and between behavioural risk factors such as exposure to air pollution and health outcomes (Corneil et al., 2006). Whereas the early focus on the spatial distribution of disease has taken a backseat (for example, Gould et al., 1991). The potential for the disease ecology approach to be extended to embrace a political ecology of disease was advocated by Mayer (1996:442) based on May's (1954) understanding of disease as usually a "combination of human activity and 'natural' characteristics of the environment that explain the distribution of disease and disease foci in populations and cultures." While Mayer's success in achieving a cohesive agenda for the political ecology of disease in medical geography has been limited, a stronger focus on the politics of AIDS and disease is evident in much of the recent research emerging out of other parts of the sub-discpline (Faubion, 2007; Pope, 2007).

3.1.3 Health Services Research

Less controversial than disease ecology but equally important to the foundation of medical geography is the tradition of health services research. Geographers have contributed to health services research in three significant ways; first, through a focus on the ways in which funding and service environments influence the provision of health care (e.g., Barnett and Barnett, 1999; Smith and Ford, 1998); second, through the establishment of a rich body of literature examining the nature of access to and utilization of health care (e.g., Joseph and Phillips, 1984; Rosenberg and Hanlon, 1996; Sherwood and Lewis, 2000); and third, geographers have explored the siting of health care facilities (e.g., Chiotti and Joseph, 1995).

As the themes of health services research illustrate this body of work has drawn heavily from empiricist traditions providing descriptive accounts of health systems and drawing from rich sources of user data (Kearns and Moon, 2002). The sources of influence of health service literature is methodologically more varied than disease ecology approaches but still heavily tied to positivism and derived, according to Litva and Eyles (1995:7), from economics, epidemiology, and behavioural research: "These methods allow the conversion of all dimensions of health problems to measurable, quantifiable characteristics – referred to as 'facts'" (Litva and Eyles, 1995:7). While these approaches strengthen our ability to understand societal trends limitations do arise; Dyck and Kearns (1995), for example, cite the failure to look beyond current and future health system patients to understand health and health care in its broader sense. Today, health service researchers are increasingly engaged with humanist streams of thought leading to questions around the personal implications of particular health care uses; others still are engaging more with poststructuralist thought and becoming critical of the processes which shape our health systems and the availability of health services.

As health geographers began to distance themselves from the 'parent' discipline of medical geography, the disease ecology research focus became the subject of criticism from a range of sources. In 1991, Bennett claimed that "[m]edical geographers have seldom recognized the deeper philosophical significance of their technical and methodological concerns (1991:339)” Kearns and Moon (2002) describe the focus as having been ‘introspective,’ and Brown and Duncan (2002:361) argue that medical geography was seen as “reductionist, determinist, essentialist and, above all, profoundly a(nti) social.” This discontent signalled the opportunity to pursue a new geography of health outside of the shadow of epidemiology and the strong influence of medicine, (Kearns and Moon, 2002), focusing on the social relationships between places and the health of populations.

3.2 EPISTEMOLOGIES OF HEALTH GEOGRAPHY

Oliver (1992) argues that an interpretive or ‘qualitative’ paradigm exists as an alternative to the positivist paradigm dominating earlier social science research; Oliver (1992) explains: “The assumptions underpinning this are very different to those of the positivist paradigm; that there can be no unity of method for the social world is a meaningful place, a world full of active subjects not passive objects; that research should attempt to understand the meaning of events, not their causes; and that research is a product of researchers and cannot be independent of them.” While Oliver (1992) is correct that qualitative researchers may not seek to generalize assumptions about events and their causes, most researchers do go beyond contextualising an issue to seek an understanding of why certain events come about – even if it is solely at the individual level. Oliver’s (1992) universal qualitative paradigm fails to acknowledge the rich theoretical and epistemological traditions that have emerged in association with qualitative methods. Indeed, I question whether one qualitative paradigm may exist given that its presence would have been shaped by the competing perspectives of feminist, phenomenologist, poststructuralist etc. approaches and their conceptualizations of how research should be carried out.

The call for a distinction between the medical and health geography research traditions has been sourced back to the work of Mayer (1996), who distinguished between the disease ecology and health service research foci of the sub-discipline (Rosenberg, 1998). Thematically, the distinction between medical and health geography is seen to hinge on a re-centring of the role of place in shaping health in a move which distances health geography from the biomedical models of health, which have been a focus of medical geography "Disease was no longer to be seen as simply a biological phenomenon; the body was no longer to be regarded solely as a site of pathological lesion(s) and curative biomedical interventions were no longer to be viewed as the primary means of securing better health" (Brown and Duncan, 2002:361). If we dig a little deeper, it becomes clear that the thematic innovations within the sub-discipline are connected with broader epistemological changes within social and cultural geography which belatedly came to influence the direction of health geography. The sense of place explored in much of the therapeutic landscape literature (Gesler, 1992), for example, can be traced back to cultural/humanist traditions that became popular in the 1970s in geography through work such as that of Yi Fu Tuan (Curtis and Jones, 1998:647). Humanist influences play a lesser role today in health geography research, but the qualitative methods with which they are associated continue to dominate research practice.

The movement away from empiricism within medical/health geographies is consistent with the emergence of theoretical frameworks which question the existence of, or at least our ability to represent an external world objectively. Dominating the epistemologies of health geography have been the humanist traditions mentioned earlier, social constructionist perspectives and radical/critical approaches which, in contrast to empiricism which is concerned with developing models of the real world, share a focus on the application of theory as a means of assisting in our interpretation of empirical research. As we have become more concerned with the nuances of social theory, the importance of epistemology in shaping research has been minimized and, with the exception of work by feminists, rarely do we make the connection between method and epistemology. Indeed, Heyman (2007) singles out feminist epistemologies as pioneering geographic critiques of positivist ways of knowing.

Epistemology, theory, and methodology have become blurred in our research as we fail to question what our epistemological assumptions mean for our research and the way in which it is carried out. Too rarely are the connections between a theoretical framework and its epistemological implications for the practice of research made clear. As Curtis and Jones (1998:656) observe in a review of the qualitative and quantitative advances in studies of contextual effects on health inequalities: “The results do not always seem consistent. This may partly be because of differences in the theoretical frameworks on which research is based (which are sometimes implied rather than clearly stated) leading to differences in research design.”

This clarity between theory and epistemology may be a function of the practice of ‘borrowing’ from more methodologically developed research paradigms, leaving the ontological implications of the governing epistemology behind; particularly, I am thinking of the use of feminist methodologies in research which has little or no commitment to addressing women’s positions in society. This practice is fairly common in qualitative research: “Researchers may legitimately choose a particular research method because of its apparent correspondence with their epistemological commitments, but that does not mean that use of the method concerned inevitably implies these epistemological commitments” (Williams and May, 1996:xii). Curiously, the epistemological and even the methodological framework of a research project is rarely questioned within the research community instead the application of the research methods appear most often as the subject of discontent. If we are to believe Bennett (1991), this may be seen as a failure to develop standards by which research may be judged. More likely this practice illustrates a lack of engagement with the epistemological and methodological commitment of a given theory within the broader literature. This weakness in the literature is a concern for the production of qualitative research insofar as researchers who are not adequately trained in epistemology may revert back to positivist strategies and seek to draw generalizations from qualitative data, an issue common in the early years of qualitative research (Bailey et al., 1999).

Theory is fundamental to health geography research, as with social geography, and is influenced by the philosophical and epistemological leanings of the researcher (Johnston et al., 1998 in Panelli 2004:19). The way that health geographers use theory differs significantly from medical geography as it is less an effort to 'model' the real world and more an effort to explore the world from a given perspective (Pannelli 2004:19). Indeed, Litva and Eyles (1995:5) point out that while medical geography appears largely 'atheoretical', it is merely that the theoretical underpinnings are not made explicit. The relationship between epistemology and theory is examined in greater detail in Table 3.1

Epistemology	**Theoretical Leanings**	**Streams of Health Geography**	**Examples of Work**
Empiricist	Structural Functionalism Positivism Realism	Disease Ecology Spatial Epidemiology	Santos et al., (2006) Gould (1991)
Humanist/ Hermeneutic	Existentialism Phenomenology	Therapeutic Landscapes Life worlds	Gesler (1992) Wilton (1996)
Social Constructionist	Postmodernism Poststructuralism Symbolic interactionism Feminist-postmodernist	Therapeutic Landscapes Geographies of Mental Health Embodiment	Kearns and Collins (2000) Parr (2000) Moss and Dyck (2001)
Critical/ Radical	Feminism Post-Colonialism Radical Critical Participatory	Women's Health Globalization & Health Critical Disability Studies	Ellaway and Macintyre (2001) Chouinard and Grant (1995) Kesby (2000) Kalepini et al., (2004)

Table 3.1: Health Geography and its Epistemological and Theoretical Influences

where recent work of health geographers is categorized by its epistemological traditions. Table 3.1 provides an indication of where participatory geographies fit in the scheme of the dominant epistemologies of health geography, specifically within a radical/critical framework alongside other activist-oriented approaches such as feminism and post-colonialism. It shouldn't be surprising, therefore, that most participatory strategies employed in health geography have related to globalization, critical disability studies, and women's health.

Drawing from Table 3.1, the following sections detail the dominant themes which have emerged in health geography and seek to connect those themes with their theoretical and epistemological traditions. This overview is not an exhaustive list of all themes covered by health geographers but, rather, an overview of those issues which have dominated discussions since the qualitative turn saw the emergence of health geography.

3.2.1 Humanism & Health Geography

The humanist or cultural turn in geography is marked by the use of qualitative methods to gain insight into the personal experiences of health and health care. Taking place at the individual level of analysis, humanist epistemologies recognize the differing impact places have on different people: "Whether they are idealists or not, humanist geographers place emphasis on the mind's interpretation of phenomena: one understands a cultural landscape by understanding the thought behind it (Gesler, 1992:737)." Much of this research has been focused on the impact of restructuring on specific places, community action in response to health threats (Kearns and Moon, 2002), and the importance of places as therapeutic landscapes.

3.2.2 Therapeutic Landscapes

Investigations into therapeutic landscapes are perhaps the most controversial of the health-related research themes representing the influence of cultural geography to gain an understanding of historical sites as places of healing unique to the experiences of the individual (Andrews, 2004). Therapeutic landscapes emerged as a research theme for health geography in the early to mid-1990s, initially with the work of Gesler (1992) but sourced from Tuan’s (1974, as cited in Gesler, 1992) notion of ‘fields of care’ as relationships and places of comfort which are sensed rather than seen.

The therapeutic landscape literature can be broadly categorized into two subsets: ethnographic and experiential studies. The ethnographic literature draws heavily on notions of symbolic landscapes and in seeking to reveal the cultural significance behind particular places (Gesler, 1992) may be equally at home within social constructionist frameworks. Examples of this work include Wilton and DeVerteuil’s (2006) examination of alcohol rehabilitation programs as therapeutic landscapes vulnerable to the tensions of surveillance; Moon et al., (2006) analyse of the representation of former asylums in contemporary landscapes; and Kearns and Collins (2000) discuss health camps in New Zealand. Experiential studies, in contrast, are more concerned with the meaning of therapeutic places to each individual and primarily use interviews as the means of investigation. Examples of this work include research by Milligan et al., (2004) and Conradson (2005), both focussing on the meaning of therapeutic places to seniors. For a more in-depth discussion of the connections between the therapeutic landscape literature and humanism see Williams (1998).

3.2.3 Social Constructionism & Health Geography

Perhaps most importantly, health geography has been founded in social constructionist research traditions, representing a shift in our understanding of the knowledge that we, as researchers, have access to. The social constructionist viewpoint, founded on the argument that common understandings of the external world are socially produced, has been the parent to theories such as postmodernism and poststructuralism spawning a body of work that likewise rejects the possibility of one universal truth.

Following the example of the parent discipline, health geography became endeared with social constructionism in the 1980s and 90s, an epistemology that reflects the diversity of theories regarding the outside world and/or the social systems inherent to it. Social constructionist thinking in health geography is broadly extending into health service research as well as work on therapeutic landscapes. Social constructionism is most engrained in discussions of embodiment, risk, and mental health geographies.

3.2.4 Risk

The notion of risk is fundamental to the ‘new’ public health (Brown and Duncan, 2002); however, the concept was first taken up by health geographers informed theoretically by Foucault and concerned about the element of governmentality increasingly prevalent in health promotion (Philo, 2000). Foucault’s (1976) interests are centred on the increased role of surveillance as a tool drawing on the moral imperative to shape healthy behaviours in spaces previously outside of medical reach. Brown and Duncan (2002:364) focus on the work of Armstrong (1995) to explore the notion of surveillance medicine as a means of expanding the medical gaze to focus in on those lifestyle and environmental factors which may be associated with some *future* risk of ill-health quite divorced from current experiences of health: “Put differently, this critically informed literature views the discursive practices of the ‘new’ public health as representing new forms of governance, regulation and social control (Brown and Duncan, 2002:364)”

A review of the risk literature raises a number of contradictions that suggest the concept is still in its theoretical infancy. There are those that argue that the new public health has moved away from focussing on specific, dangerous health hazards (Curtis and Jones, 1998:649) and others who argue that the new public health has renewed a focus on the dangers of our physical environment (Collins, 2007). Perhaps a distinction needs to be drawn between the kinds of research that construct the new public health, (which typically considers multiple risk factors stratified by social characteristics to identify the relative risk to specific populations)[9] versus the *messages* of the new public health which seek to send unambiguous guidelines for reducing the health risks one is exposed to. In this respect, we see a disconnect between the research being carried out and the health promotion strategies being employed.

> Importantly, we would argue that [the new public health] agenda would act to reunite the programme of research that we are suggesting with the broader ambitions of the health geography project. More specifically, a good deal of the critical ‘new’ public health literature remains at an abstract or theoretical level. Only partial progress has been made towards the understanding of how the discursive practice of the ‘new’ public health movement works in particular place-based settings
>
> (Brown and Duncan, 2002:266).

3.2.5 Radical/Critical Epistemologies & Health Geography

Radical geographies emerged in the 1960s as a means of giving voice to the multitude of political and social movements which have come to characterize the era (Heyman, 2007).

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[9] Jones and Moon (2002:613) cite the extensive work carried out by McMaster University health geographers into environmental risk factors.

Uniting the various theoretical and methodological traditions of radical and critical geography are the goals of revealing how underlying structures of power exclude and oppress, or in Gleeson's (1997:206) terms, coming to understand how: "oppression and exclusion arise from the sociocultural production of space." The plethora of literature identifying the presence of health inequalities and addressing the (in)effectiveness of neo-liberal health care policies is identified by Kearns and Moon (2002:615) as evidence of the commitment of health geographers to the goals of social justice critical geographies work toward. Kearns and Moon, however, are a little more modest when discussing the extent of the reach of critical geographies: "as critical health geography has taken root, a modest blend of activism and academic pursuit has emerged as a viable possibility." (Kearns and Moon, 2002:616). On the critical geography agenda is the achievement of social change, something which health geographies have traditionally been engaged with through formal avenues:

> Health geographers often seek to influence those who make or interpret policy, or who plan for, or provide, health care services. Is it more effective to do this through insurgency or collaboration? The challenge, perhaps, is to seek out levers of change beyond the more obvious ones held by those in positions of power. Critical perspectives on cherished policies are not always welcome and there is a gulf between academia and the policy world that is more easily bridged as an insurgent microscale researcher than as a policy consultant.
>
> (Kearns and Moon, 2002:616).

3.2.6 Critical Disability Studies

Fundamental to geographic discussions of disability have been criticisms of the built environment and its exclusion and marginalization of persons with disabilities. While there is a rich array of disability literature emerging out of social geography I will focus here on that which can be described as critical – primarily the work of Vera Chouinard, Brendan Gleeson, and Rob Kitchin.[10] Independently these authors have documented the limitations of state efforts to deinstitutionalize care for the disabled, particularly in the face of resistance from communities (Gleeson, 1997); the everyday struggles of living with a disability (Moss and Dyck, 2001), and the need for 'enabling' research involving persons with disabilities (Kitchin and Wilton, 2000).

Gleeson (1997) provides a social justice framework for the critical disabilities literature by exploring the concept of 'enabling justice' as a means of challenging the limitations of existing theoretical and policy frameworks for addressing the needs of disabled persons in society. Gleeson's (1997) concept of enabling justice differs significantly from the concept of social justice with its connections to the welfare state by dismissing the notion of equally distributing resources and working instead to ensure "individuals and groups are enabled to participate in the mainstreams of social life in meaningful ways" (Gleeson, 1997:205). Gleeson (1997:205) specifies that this framework of enabling justice has two key dimensions which must be met; firstly, material satisfaction and, secondly, social participation. It is this very failure of academia to produce an enabling environment which is a source of criticism by Chouinard and Grant (1995). Chouinard and Grant (1995) document the shortcomings of feminist geographies in their inability to make room for the bodies and experiences of disabled women. Most pertinent to this discussion, however, is the growing body of participatory research being carried out by geographers engaged in critical disability studies. These authors identify the need for research to engage with marginalized groups by supporting their pursuits of social change, this is discussed further in section 3.3.2 with reference to Wilton (2001) and Kitchin (2004).

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[10] For a broader review of the disability studies literature in geography see Park et al., (1998).

3.3 A PARTICIPATORY PARADIGM FOR RESEARCH

Participatory approaches are often discussed in terms of their revolutionary methods; however, this is short changing the approach somewhat as underpinning these methods is the valuing of alternative sources of knowledge that span much deeper than simply a new research method. In much the same way that Darlaston-Jones (2007:21) views a move from objective to subjective methodologies as requiring “a major epistemological shift away from empiricism toward constructionism”, the valuing of those who would otherwise be constituted ‘lay persons’ as experts in the interpretation of their own realities requires the development of a participatory research paradigm.

A participatory research paradigm reflects the goals of research oriented toward the achievement of positive community change both societally as an outcome and a group process. In this respect a participatory paradigm represents a reinterpretation of who is qualified to carry out research, questions the structures of academia, and works to overcome oppression in society. The work of Paulo Freire (1970) is fundamental to understanding a participatory paradigm as Freire (1970) considers knowledge not something to be contained within ivory towers but embedded in the social realities of those who live through oppression. In terms of research epistemologies CBPR rejects many of the values ingrained in positivist science and works toward a new understanding of social life embedded in the critical research traditions preceding it, particularly feminist and radical perspectives.

3.3.1 Participatory Research in Geography

Participatory research methods have a long history in regional geographies and development studies but their use is rapidly increasing in social geographies evidenced by the addition of participatory action research chapters in geography methods texts (Kindon, 2005), the forthcoming text devoted to participatory geographic work *Participatory Action Research: Connecting People, Participation and Place* (Kindon et al., in press), the presence of progress reports on participatory methods in *Progress in Human Geography* (Pain, 2004), and the number of articles in journals such as *Area* devoted to studies drawing on participatory methods. Most significant in this body of participatory geographic research is the focus on methods that enable place and space to be interrogated in new ways, for example, through the use of photo diaries (Bijoux and Myers, 2006; Thomas, 1997), participatory video (Kindon, 2003) and participatory mapping (Kesby, 2000).

Predominantly overlooked in the body of participatory geographic literature is work emerging out of the Detroit Geographical Expedition and Institute (DGEI) from the 1970s. At its core were notions of community participation and social change (Heyman, 2007). This work drew upon Freire's (1970) pedagogy to conceptualize research in a similar frame to that of community-based participatory research and came about, Heyman (2007) explains, due to awareness that rather than researching on behalf of the black population living in ghettos was inadequate the opportunity to produce knowledge needed to be put in the community's own hands; this materializing in the establishment of a community-based education and research programme:

> DGEI geographers saw knowledge as fundamentally a political, not a technical problem: solutions to social problems demanded not simply *more* knowledge, but wider access to the means of knowledge production. The DGEI was founded not simply to refocus the topics of research towards poverty and ghettoization, but toward breaking the cycle of expert knowledge production as a central goal of radical geography.
>
> (Heyman, 2007:101)

Heyman (2007) conceives of the DGEI movement as primarily about education: transferring skills and enabling a broader perspective of the world though he stops short of adopting Freire's terminology of conscientization and is critical of others who have interpreted the DGEI movement as research-oriented. At the same time, DGEI "represented a wholesale reconceptualization of the social role of geographical knowledge production, and the role of the geographer in social change" (Heyman, 2007:106-7). Despite the enabling discourse, the DGEI was tainted with prejudice, including sexism and racism (Katz, 1996, as cited in Heyman, 2007:107), and continued to draw upon positivist research paradigms (Merrifield, 1995). Ultimately many of the geographers involved in radical movements such as the DGEI faced academic 'exile' for their opposition to the dominant geographic standpoints (Merrifield, 1995:53).

The most important contribution the work of DGEI geographers made to present-day discussions of community-based participatory research is with regards to the role of the researcher. In their pursuit of social education and change this group raised the issue of whether geographers should adopt the roles of social mobilizer, advocate, and activist. Campbell (1974), for example, talks at length of the duties of the advocate geographer as educators and problem solvers who work with communities to become problematizers, he explains: "Radical science must be based upon a personal committment [sic] to genuine communication with others in an attitude of mutual respect. Action divorced from radical ideology may be counter-productive in that it may result in an eventual re-enforcing of the status quo" (Campbell, 1974: 103-4). What geographers shouldn't be, argued Bunge, (no date, as cited in Merrifield (1995:63) is community organizers as they risk instead stunting the mobilization of a grassroots community base necessary to the success of a truly community-based initiative; an issue discussed in Chapters Ten and Eleven.

Participatory geographic research, like the wider participatory literature has focussed extensively on the role of the researcher in fostering community relations. Participatory researchers have been active in establishing what Routledge (1996) terms a 'third space' for 'critical engagement' which connects the academy with the activist world where geographers contribute to causes and community organizations while constantly reflecting on how their own positions impacts on, and is impacted by, these very different worlds:

> In my own experiences it is not clear to me where one 'role' or position begins and where the other ends. This blurring holds out the possibility that 'insider' and 'outsider' voices may coalesce into a new perspective, one which is not just counter-hegemonic or simply oppositional (thereby remaining within the discursive frameworks and structures of the dominant), but which opens a new arena for negotiation, meaning, representation...
>
> (Routledge, 1996:414)

Within this space, however, the voices of the collaborators have been too often silent, but for their interpretation through the reflections of the researcher. Likewise, the experiences of participatory geographers are widely documented (Kindon, 2003; Kitchin, 2001) but too rarely are we seeing participatory research projects making significant contributions to our theoretical or experiential understanding of the world. If participatory strategies are going to be accepted as a mainstream approach for carrying out research the important effort of developing best practices for its implementation must be accompanied by a collection of works which provide evidence of its contribution to geographic knowledge production.

Further hindering the emergence of a cohesive body of participatory geographic research is the diversity of participatory approaches. While the employment of participatory methods in geography is becoming increasingly mainstream, the research lacks even a common goal of working toward social change. If the application of participatory methods is going to achieve more than simply offering another means by which personal experiences and may be tapped to overcome, the division between the application of participatory methods in traditional research frameworks and the all-out adoption of a participatory approach, then it must be situated within the grasp of critical/radical geographies. Without the overriding goals of achieving social justice and questioning power structures, participatory approaches are at risk of being milked for the new perspective they bring and then discarded in the same way as arguably approaches such as time geography when no new knowledge is forthcoming.

This research contributes to the theoretical body of participatory geographic literature through this critical examination of CBPR, a more participatory research strategy within this field of geography. I draw on the work of Freire and Bourdieu to ground the conceptual work of participatory geographies thereby extending avenues for debate regarding the connections we make between participatory theory and method. Most significantly this research, in examining CBPR and explicitly drawing on stakeholders perspectives, allows a balanced understanding of the circumstances under which participatory strategies are successful and the extent to which we should be pushing for participation in geographic research.

3.3.2 Participatory Research in Health Geography

Participatory research has been largely overlooked in health geography and examples of community-based participatory research are virtually absent. Amongst those health geographers who have made a theoretical contribution to participatory geographies are

Kesby (2000) and Wilton (2004). Like many participatory researchers, Kesby (2000:432) raises the issue of how we can conduct praxis oriented work "while at the same time meeting the criteria which [our] embeddedness in an audit-oriented academy dictates." Kesby's (2000) solution is the use of methods, such as participatory diagramming, which facilitate political action. Similarly reflective, Wilton (2004) discusses his position as an academic researcher, negotiating his position as an activist and thus also a group member. Wilton (2004:120) concludes that in carrying out activist work researchers need to allow sufficient space between themselves and the group as a means of diffusing any potential power discrepancies: "For disability activists, researchers must be responsive to the concerns of the group with which they work, but they must keep their distance to avoid undue influence and impact on those groups."

Participatory methods have long been employed in developing country settings; it is not surprising, therefore, that participatory research has been applied most intensively by health geographers to address HIV/AIDS in Africa. Thomas (2007) applies diary methods as a means of accessing knowledge of the emotional experiences of living with HIV/AIDS in Namibia. Thomas (1997) portrays the central role HIV/AIDS can take in shaping one's emotional life as the experience of stigma reshapes one's personal identity and sense of wellbeing. Kesby (2000) similarly documents the use of participatory methods, in this instance participatory diagramming, with people living with HIV/AIDS in Zimbabwe applied within the context of an action research project, a framework he sees as significant for its potential to turn research findings into objectives for future research. Kesby (2000) emphasises the value of participatory diagramming as a tool for working within group contexts giving voice to those who may otherwise not be heard (e.g., by distinguishing unmarried women from married women etc.).

This body of participatory disability research is further extended by McFarlane and Hansen (forthcoming) two disabled women activists who assembled advisory committees of disabled persons to assist in the design of their research into employment and reproductive concerns. The two researchers carried out interviews but fostered a reciprocal relationship with stakeholders and found the participating women had little interest in continuing their involvement in academic activities such as the publication of academic papers. Most pertinent to the current research is work by Rob Kitchin (2001) documenting his experiences and frustrations applying participatory action research with persons with disabilities in Ireland. While Kitchin’s (2001) work will be discussed in greater detail in later chapters, it is important to note that he experienced considerable frustration with the process due to the his personal relocation during the research process and the inability or unwillingness of persons with disabilities to commit to the process. This led him to advocate for the development of alternative research strategies that work toward similar goals of empowerment.

As Gleeson reminds us:

> Of course, an enabling geography must do more than identify empowering research methods: it must also locate, and engage with, the political arenas of disabled people and their various movements. The task of engaging with disability is unavoidably challenging for researchers: it demands both that we think politically about our work and that we expose ourselves to direct political evaluation.
>
> (Gleeson, 2000:68)

Participatory research in health geography has largely been limited to the adoption of participatory methods, particularly within developing countries. Those more holistic participatory approaches (implemented by Kitchin, 2001 and Wilton, 2004) have largely gone under the radar within health geography and failed to register a need for more inclusive methods of research found within the wider discipline. This research addresses a significant gap in our knowledge of how participatory strategies may be best applied with populations who have compromised health or are living with disabilities by examining research strategies which benefit community members. I also provide a perspective on how participatory research may contribute to health geographies and even whether it is an approach we should be adopting.

3.4 SUMMARY

The sub-discipline of medical geography has undergone dramatic epistemological changes in recent decade; the result being the emergence of what some term ‘health geography’ – geographic research that is attuned to the important role that place plays in mediating both health and health care. Dominating health geography has been humanist, social constructionist and critical epistemologies, a significant departure from the largely positivist disease ecology and health services research approaches employed in medical geography. The emergence of these considerably more theory driven epistemologies has led health geographers to question many of the assumptions underpinning biomedically influenced research and to consider new ways through which we might represent the experiences of health care users.

The work by critical geographers has provided an epistemological foundation for questioning the power structures that dominate research interactions and for working toward a framework of research that addresses societal inequalities. The area of critical disability studies has been at the forefront of pursuing more ‘enabling’ forms of research in which those living with disabilities are active; this is evident particularly in the work of Kitchin (2001) and Wilton (2004). While this research does not speak specifically to the nature of carrying out participatory research as a geographer, it does raise a number of questions regarding which participatory strategies are most suited to which groups and how we may carry out research in a manner that ensures control remains with those affected by the issues at hand.

Chapter Four

Social Capital Theory & Participation in Civil Society

Community-based participatory research (CBPR) combines the tasks of community building, education, and research into a process of social action. Most significant in distinguishing CBPR from other forms of participatory research is the element of community building which seeks to enhance the social capital of civil society. Participatory research approaches are founded on the belief that engaging lay community members in the research process will contribute to the empowerment of individuals and, in turn, facilitate community mobilization to overcome oppression. While the ultimate goal of participatory research is to shape communities in positive, healthy ways, communities themselves also have the potential to shape participatory research and in this sense the structure of communities, or their social capital, may be an influential force. As I progressed in the fieldwork for this study it became clear that social capital had an important role to play in the attraction of participants into a participatory research project and the evolution of the project as new stakeholders were drawn to participate. So what does it take to build communities and how do we know that community engagement will have positive impacts? To resolve these issues an understanding of social capital in the context of communities is required.

This chapter elaborates on the nature and meaning of social capital so we may better address the causes for its decline in Western societies, why its distribution has become an issue of social justice, and how the concept is useful in developing our understanding of the CBPR process. The use of social capital theory, as with most social theories, is as a coherent structure to tie together my own ideas, the wider literature, and research findings so that the topic under study may be better understood; this is a notion Clarke (1997:85) expands on in relation to her use of social worlds theory: “What is important to me as a pragmatist is whether social worlds theory helps in the process of discovery, opens analytic doors, and provides entrée into chaotic data and a useful analytic framework. If it does so, the theory will continue to be built and refined on firm empirical foundations.” This discussion aims to establish the foundations of a framework for understanding how social capital is fostered at the individual level, something which has been lacking in recent research in the area.[11] In building this foundation I draw strongly from the work of Pierre Bourdieu (1984, 1986) who sees social capital as an instrument with the potential to reduce societal disparities in quite concrete ways across generations. Bourdieu’s (1984) perspective is useful to the present research as he offers an understanding of how inequities, and the behavioural patterns that they produce, become cemented in society thereby offering a starting point from which new patterns of societal support may emerge.

4.1 INTRODUCING SOCIAL CAPITAL

Social capital has captured an extraordinary amount of attention in the past decade despite unresolved arguments over what exactly it is, how it is created, and why it is in

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[11] The paucity of research in this area may be a result of weak connections between the individual and societal level impacts of social capital. Only recently has research begun to explore this relationship with Poortinga (2006) finding that positive connections between social capital and health are present at both the individual and national scales.

decline. This decline is witnessed in the lower number of people belonging to voluntary associations, choosing to volunteer and trusting in their neighbours and their governments and is termed ‘civic malaise’ by Deijerm and Uslaner (2001:1). The social capital debate has taken place amidst dramatic social shifts within Western society as divorce rates have increased[12], crime and victimization[13] risen, and fertility decreased[14] to create what Fukuyama (1999:60) has termed ‘The Great Disruption.’ These societal shifts have been accompanied by institutional shifts: governmental input into everyday life has declined as individuals demand greater freedoms and governments are increasingly tolerant of diversity – whether it be sexual (in the form of gay marriage), ethnic (via looser immigration policies), or economic (policies increasingly help the rich get richer) (Fukuyama 1999).[15] These broader social changes are intricately connected to possibly an even greater social shift towards a culture of individualism as our social ties play a diminished role in our lives and in the maintenance of society (Fukuyama, 1999).

In this chapter I delve into the contrasting work of Fukuyama (1999), Jacobs (1961), and Putnam (1993); collectively these authors provide us with a theory of social capital that emphasizes the impact of engagement on the functioning of society at all levels including the cooperative behaviours of individuals, the collective efficacy of communities, and the responsiveness of governments. These authors have stressed the importance of the social

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[12] Hall (2002), however, has looked at the influence of divorce rates and the evolving role of women on social capital and found them to have only a minor role to play in the decline of social capital in Britain, suggesting the same findings are likely to apply to other countries with similar divorce rates.

[13] Survey measures have shown an increase in incidences of victimization across Canada in recent years while reported rates of crime have been subject to an overall decline since 1991 (with the exception of homicides and other serious violent crimes which have increased) (Statistics Canada, 2004 and 2005). Some element of this decline may be attributable to a decrease in reporting of non-serious crimes such as theft.

[14] Fertility rates reached a record low in Canada in 2004 (Statistics Canada 2004a).

[15] With the exception of the post-September 11 law changes which have led to governments regaining control and information regarding the movements of individuals.

networks of individuals to the civic engagement of populations, and thus the sustenance of participatory democracies. However, a distinction must be made between social capital and civic virtue. While social capital refers to those social relations which foster cooperative attitudes, civic virtue is the propensity to act cooperatively, without networks of social capital one may simply be working alone and contributing little to the good of society (Putnam 2000). It is through social networks that values such as trust and reciprocity are supported, enabling us to work with one another in the interests of the common good and thus influence society beyond our own community. The interconnections between individuals, communities and governments in the production of social capital is a theme that re-emerges throughout this thesis.

4.1.1 Defining Social Capital

The term 'social capital' has been reinvented at least a half dozen times and is based on principles that are widely acknowledged – albeit not under the banner of 'social capital'.[16] The original use of the term appears to date back to Tocqueville (1832) a French writer who, on traveling through the US, observed the communitarian spirit of Americans (Field 2003, Putnam 2000). Tocqueville believed the sheer level of participation by Americans in voluntary organizations served to form a 'social glue' cementing everyday Americans together (Field 2003). These voluntary networks were perceived to be more favourable than the formal, hierarchical networks Tocqueville (1832) noted as prevalent in Europe at the time; and whose presence Durkheim lamented in Feudal societies for their inflexible foundation in one's position and status (Field 2003:11). The American experience of social cohesion was perceived to offer an

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[16] Phrases like: *'It's not what you know, it's who you know'* reflect how engrained social connections are as a personal resource yet authors continue to critique the concept for its lack of originality (see Portes, 1998)

alternative means by which an ordered and cooperative society could be maintained without an explicit reliance on social hierarchies.

Despite the clear economic impact of social capital use of the term ‘capital’ itself has been heavily contested due to the economic insinuations. Non-economists are particularly resistant to the implication that the term social capital is, like other forms of capital, transferable and able to be cashed in (Whitehead and Diderichsen, 2001). Social researchers, particularly sociologists who appear most sensitive to the ‘creep’ of economics into social theory, object to the use of an economic framework to capture the value of social networks arguing that it leads us to view the concept through a lens which overlooks the inherent power imbalances (Fukuyama 1999; Whitehead and Diderichsen, 2001). Social capital fails as a form of capital because it cannot be reduced to a currency despite allegedly having “a high degree of transferability as human capital” (Whitehead and Diderichsen, 2001:137). The transferability between social capital and human capital is disputed by Ostrom (2000) who adopts a network-based understanding of the concept to argue that social capital is situated in the community and is produced through efforts that do not reflect immediately on the capacity of individuals (Mohan and Mohan 2002). When social capital is viewed more purely as a resource, Ostrom’s (2000) argument becomes invalid as our networks become a source for furthering our education, social standing, and employment prospects. Due to the difficulty of quantifying the value of social capital in dollar terms, the concept has proven to be a somewhat problematic for economists many of whom share Bourdieu’s (1986) view that economic capital is of overriding importance in shaping all forms of capital. Economists have, however, made progress exploring the importance of social capital to markets (Fukuyama 1999; Grootaert, 2001).

> So it has to be posited simultaneously that economic capital is at the root of all the other types of capital and that these transformed, disguised forms of economic capital, never entirely reducible to that definition, produce their most specific effects only to the extent that they conceal (not least from their possessors) the fact that economic capital is at their root, in other words – but only in the last analysis – at the root of their effects.
>
> (Bourdieu, 1986:252)

Theorizing based on the market model of social capital has also been fruitful due to the inequitable distribution of social capital in society. This has led Wunthrow (2002) to hypothesize that the present Western decline in social capital is a response to the resource being used as a tool for exclusion and social polarization. While some groups have been able to use social capital to their advantage this has led “some segments of the population to feel unwelcome and to cease participating, or failing to provide the resources that people need to engage in civic activities.” (Wunthrow 2002:79) This hypothesis becomes even more compelling when we consider Bourdieu’s (1984) observation that members of an ‘outside’ group tend to subscribe to their outsider status through a process of ‘category differentiation’ aligning themselves with the practices or resources which are available to them while dismissing those outside of their own economic or social status. In this sense, social exclusion from the processes of civic participation may become a source of social identity whereby the excluded see social participation as an activity for other ‘kinds’ of people. This theorizing is compatible with Freire’s (1970) understanding of the divisions between the oppressed and the oppressors, the need he sees for the oppressed to come together and draw from their collective social capital is a clear indication of a shortage of the resource amongst the underprivileged in society. Social and employment activism has also long drawn on resources of social capital and is the basis upon which trade unions and neighbourhood watch groups are formed (Whitehead and Diderichsen, 2001).

Social capital, in its broadest sense, refers to the networks we, as individuals, accumulate throughout our lifetime and which, through the sharing of common values, act as a resources (Field, 2003). Wunthrow (2002) identifies associations, trust, civic participation, and volunteering as the primary forms of social capital as they produce relationships that may be used to improve one's community. While it is the experience of individuals that is the focus of definitions of social capital by Putnam (1990), others such as Capriano (2006) reject this approach arguing that networks are the means through which social capital is distributed. Wunthrow (2002) is similarly critical of current understandings of social capital, arguing the concept as Putnam (1990) understands it is a weakness of current research. Meanwhile, Bowles and Gintis (2000) believe that 'community' would be a better reflection of social capital's foundations in effective local governance.

For Carpiano (2006:166), social capital should more accurately be understood "as consisting of actual or potential resources that inhere within social networks or groups for personal benefit." This resource-driven understanding is more consistent with the work of Bourdieu (1986) as it allows for the possibility that all social connections are not equal, and that resources accessible through one person's family or friends may differ with socio-economic status. Capriano's (2006) definition of social capital, however, deviates from earlier work on the topic where the means through which social resources are shared has been the focus. In contrast, Fukuyama (1995:10), for example, describes social capital as "the ability of people to work together for common purposes in groups and organizations." While I agree with Capriano that the resources possessed by social networks have potentially the most transformative impact on the lives of individuals, this approach runs the risk of undermining the important day-to-day impact of resources – such as adults watching over a playground – which has a significant role in shaping safety and cohesion within communities and may not be associated with socio-economic status.

The present interest in social capital comes about as we face growing evidence of its decline in Western societies, a trend most extensively documented by Putnam's (2000) US based research in Bowling Alone: The Collapse and Revival of American Community (see also Coleman 1988, Field 2003, Fukuyama 1999, Putnam 2002). We seem to be deep in the midst of a serious case of 'you don't know what you've got until it's gone' as researchers from a variety of disciplines work to document the positive impacts of social capital on society. To date, we know that groups with high levels of social capital experience better health, are less fearful, have more confidence in government (Putnam 1993), are more confident of the difference they can make to society,[17] and tend to be wealthier. Of particular interest to the current research is the growing body of work exploring the relationship between social cohesion and health. Lomas (1988:1181) believes that "the way we organise our society, the extent to which we encourage interaction among the citizenry and the degree to which we trust and associate with each other in caring communities is probably the most important determinant of health" and Veenstra (2002), for example, has found civic and associational participation to be negatively associated with mortality in Saskatchewan. For more on the relationship between social capital and health from a critical perspective see Hawe and Shiell (2000).

Social capital and inequality have a complex relationship. From Putnam's (2000) evidence, it is clear that the socio-economically advantaged exhibit greater levels of

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[17] Americans have declining faith that their political voice will be heard, with three out of four Americans in the 1990s claiming that they do not trust the government 'to do what is right most of the time', a figure that contrasts with one in four in the politically tumultuous 1960s (Putnam 2000:47).

social capital. Importantly, one's access to social capital is not determined solely by socioeconomic status but may also depend on gender, ethnicity, length of establishment within a community, and any number of other factors (Whitehead and Diderichsen, 2001). Yet interestingly, the relative levels of social capital experienced along racial, socioeconomic and geographic lines have stayed the same over time in the US – all forms of social capital have consistently declined; the deduction we can make from this is that social capital may be self perpetuating. The situation is different in the UK, however, where overall levels of social capital have stayed constant but we are seeing larger disparities between the connections within different social groups (Hall, 2002:22).

4.2 SOCIAL CAPITAL & THE INDIVIDUAL

Coleman (1988) first used social capital theory in his work on education to explain differences between educational outcomes and socio-economic status (Schuller et al., 2000). Given the argument that "education is in part a proxy for privilege", (Putnam 2000:186), it is not surprising that those with more education were more engaged civically. And if we consider social capital to be the resources available through social networks it is intuitive that the economically better-off have access to greater resources. Despite evidence suggesting that social capital is disproportionately high amongst the wealthy there are also clear advantages to its presence amongst the less well off. Coleman (1988) argues that we can draw from social networks with positive impacts which transcend one's place in society - an argument illustrated through his research into education within US ghettos (Field, 2003).

While social capital may have transformative properties with the potential to elevate the status of marginalized groups, its absence can also have negative impacts on individuals

(Whitehead and Diderichsen, 2001). Caughy et al. (2003), for example, have found that in deprived socio-economic neighbourhoods where low levels of social capital exist connections with neighbours was detrimental to the mental health of pre-schoolers. Conversely, in high socio-economic neighbourhoods parents with low levels of social capital were more likely to have pre-schoolers with behavioural problems (Caughy et. al., 2003).

> ...social capital is second only to poverty in the breadth and depth of its effects on children's lives. While poverty is an especially potent force in increasing youth fertility, mortality, and idleness, community engagement has precisely the opposite effect. Social capital is especially important in keeping... teenagers from dropping out of school, hanging out on the streets, and having babies out of wedlock.
>
> (Putnam, 2000:298)

Many proponents of the concept of social capital, particularly those focusing on its importance to education, argue that its positive social impacts are most pronounced within the familial realm albeit at the expense of other sources of social capital (Bourdieu, 1990; Coleman, 1991). Coleman (1991) represents perhaps the most ardent advocate of this view as he distinguishes between primordial social relations, which are experienced through family membership, and constructed social relations which are those built up through networks outside of the home and tend to be weaker and of a specific purpose.[18] Coleman (1991) sees the present erosion of social capital as a function of weakened primordial social relations (the decline of the family), a weakening that the increasing role of constructed social relations (such as schools) cannot adequately replace (Field, 2003). These assertions are disputed by Portes (1998) and Putnam (2000) who believe Coleman is overstating the importance of familial ties, and Astone et

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[18] Coleman's belief that the family is the stronger of the two forms of social relations appears to emerge out of his application of Loury's (1977) work in which the concept is used to understand better child and adolescent development.

al. (1999) who argue that Coleman is confounding variables when he uses evidence of changing family structure to argue that the family itself is in decline. Coleman sees the need for formal institutions to substitute for declining primordial social structures in what Portes (1998:10) describes as a practice of 'social engineering.'

Putnam (1993), Coleman (1998) and Bourdieu (1998) see the first application of social capital to be within the family. As a form of familial support social capital shapes the educational and economic potential of children promoting child development. These primordial social relations can also have positive societal impacts as the presence of stable families contributes well-behaved children to the community (Putnam 2000). The problem is that most primordial forms of social capital tend to stay within the family and facilitate the transfer of social advantage and disadvantage across generations (Bourdieu 1984). The wealthy, for example, are able to ensure their children receive tutoring, have access to the best schools, and receive financial support for any ventures they choose to pursue thus increasing the likelihood of financial success. While primordial relationships may be the most influential in the development of young children, it is the relationships with those outside of the home that are primarily useful to determine levels of social capital amongst adults, perhaps because the benefits we gain from primordial connections diminish as we age. Outside of the family social capital appears to continue its positive influence at a societal level – its impact at the individual level is presently unclear.

4.2.1 The Nature of Community Networks

Despite Coleman's contentious assertion that social capital is most influential within the familial realm he offers us broader insight into the way in which social capital is fostered.

Coleman (1990:304) describes social capital as ‘embodied in the relations among persons’ it is created when individuals direct these relations toward action and in this sense increase the resources at their disposal. This understanding of social capital emphasizes social relations in facilitating achievements which would be difficult, or impossible, for an individual to attain on one’s own (Coleman, 1990). In this respect social capital, as with participatory research, may be contingent on the nature of networks to contribute resource-wise to a community.

> Social capital is defined by its function. It is not a single entity, but a variety of different entities having two characteristics in common: They all consist of some aspect of a social structure, and they facilitate certain actions of individuals who are within the structure... Unlike other forms of capital, social capital inheres in the structure of relations between persons and among persons. It is lodged neither in individuals nor in physical implements of production.
>
> (Coleman, 1990:302)

The nature of networks is integral to the formation of social capital yet we know little of how social capital influences group formation. Group dynamics have been studied in-depth in other disciplines and it appears that the type of social connections we have play an important role in shaping behaviour. Vertical social networks, for example, have been found to facilitate greater trust than horizontal or hierarchical networks where power imbalances may compromise trust (Putnam, 1993:175): “Dense but segregated horizontal networks sustain cooperation within each group, but networks of civic engagement that cut across social cleavages nourish wider cooperation. This is another reason why networks of civic engagement are such an important part of a community’s stock of social capital.” Less intimate relationships may be most important for fostering social capital at the community level particularly where diverse communities are concerned. Community networks do not simply constitute the connections between people; they also influence the forms organizations take within a community.

Putnam (1993) has theorized that the types of organization (vertically structured versus horizontally) most widely subscribed to in a society has important impacts on the emergence of social capital. The greater the number of individuals involved in groups that are horizontally organized (like sports clubs and support groups) the more civic minded a community will be and thus the government, in turn, will be more responsive. Hierarchical organizations (like most churches), in contrast, do not foster the same kind of community cohesion particularly conservative religions, which tend to focus energies inward, leading to a form of exclusive bonding social capital, a practice most extreme amongst evangelicals where forms of volunteering are almost entirely related to church activities (Putnam, 2000). Granovetter similarly argued in 1973 that one-dimensional relationships (that is, a neighbour or a co-worker but not a co-worker who is also a neighbour) are most important in providing access to resources whether it be information, money, or a job interview (as cited in Jackson et al., 1977).

> Associations and institutions provide an informal framework to organize information sharing, coordination of activities, and collective decision making. Bardhan (1995) has argued that what makes this work is peer monitoring, a common set of norms and local-level sanctions.
>
> (Grootaert, 2001:11)

Social networks are clearly fundamental to the distribution of social capital throughout society. One of the flaws of research in the area to date, however, has been the use of membership in formal organizations as a proxy indicator of aggregate social capital; rarely do networks of informal social relations, such as friends, family, and neighbours, inform population level data on social capital (Putnam 2000). There are three additional major problems with relying on associational membership as the sole indicator of social capital.

Firstly, a division has emerged between formal and informal social capital which belies the positive impacts on political participation and the construction of cohesive communities shared by both types of connections. Informal social capital often contributes just as much, if not more, to positive community effects as its formal counterpart. Putnam (2000:301) reports that informal social capital amongst adults is a better determinant of educational success amongst children than levels of formal social capital. By focusing on formal social networks we omit information on the important ties with family and friends which provide us with deeper levels of emotional support on a daily basis.

Secondly, though our understanding of the differences between formal and informal social capital has been relatively static, the exhibition of social capital through informal and formal means varies across time and space, a criticism articulated by Astone (1999). Astone (1999) points out that while members of associations have been found to be more civic in their attitudes and more likely to participate in politics, this use of associational membership falls into the trap of much social capital research which fails to take into account the potential for social and cultural differences in its expression. Even within the US, the primary location of this research to date, there have been important changes to associational membership. Membership in formal organizations is increasingly an exercise of payment not participation, a problem particularly prevalent in the arena of politics (Putnam, 2000). Putnam (2000) notes that while the number of Americans belonging to a political organization halved in the two decades preceding 1987, monetary contributions to political organizations approximately doubled. This practice appears to be just one symptom of a larger corporatization of politics in which the media plays a larger role in political promotion than social networks. Associational membership does not have the same meaning that it did in the past bringing into question how heavily we should be relying on this data which may not accurately reflect social participation. Critics of social capital suggest that perhaps it is new forms of social capital which are leading to perceptions of a decline which may in fact just be evolving (Portes 1998).

Thirdly, informal social networks are often fundamental to the establishment of formal networks and social action - suggesting that informal networks may share many of the same functions as formal networks. While associational membership may have positive implications it is not clear whether these positive externalities may be eroded by other relationships such as those within the family – we need to understand better the context of the positive and negative implications of our social relationships. Ideally measures of social networks will incorporate both formal and informal networks but also characterize the nature of these social relationships and how they change over time.

4.2.2 Social Capital & Civil Society

'Civil society' is understood by Rothstein (2002) as grounded in the relations that emerge in the spaces between the government, the family, and industry. Civil society may be enhanced through a process Chaskin and colleagues (2006:489) draw from a number of sources to define as "going beyond community-based service provision or production... to strengthen informal relationships and the organizational infrastructure of communities, and to build the capacity of communities to manage and foster community change." Amongst the most rich work on social capital to-date has been that which examines the impact of social capital on the democracy and wellbeing of civil society.

Putnam's (2000) recent work on the US aimed to explain why the country's social capital levels have been subject to a long-term downward trend. The period of time since the 1950s, in which social capital has been declining so markedly has been characterised by rapid social change which Putnam (2000) describes in terms of a globalizing economy: the reduced importance business places on civic engagement, increased hours spent at work, women becoming more involved in the workplace, and the growth of inequality within society. It was also a time of increased individualism as 'rights' and 'choices' began to triumph over other values in debates around the greater good. This individualism is best captured by Fukuyama's (1999:48) analysis that individuals have become preoccupied with their own freedoms at the expense of their responsibilities for others. But Putnam (2004) ultimately sees the impact of these societal changes as minimal for levels of social capital, arguing that workplace friends and social activity play no larger part in peoples lives than they did in the 1950s (Putnam, 2004).

There is little evidence that employment has greatly affected social participation outside of the workplace. Putnam (2000) reports that amongst women the greatest declines in civic participation has been amongst those who are not engaged in the workforce full-time. These differences may be attributable to the backgrounds of those women who choose to keep working after their children are born – and to some extent "socially active women are somewhat more likely to choose to enter the workforce than their less civic-minded sisters" (Putnam, 2000:201). Furthermore, individuals who spend more time working may in fact be more likely to volunteer.[19] Putnam (2000) goes on to suggest that perhaps it is financial stress, potentially triggered by the growth in social inequalities,

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[19] "In an exhaustive study of the determinants of participation, political scientist Sidney Verba and his colleagues found that the amount of free time a person has seems to have little or no effect on whether he or she becomes civically active or not. Just about the only social activity that busy, harried people engage in less than other people is dinner with their families." (Putnam, 2000:191)

which is leading to this decline in civic engagement as those with financial difficulties are less likely to participate in society. The problem with this theory is that social capital has been fairly resistant to economic change, continuing to grow throughout the great depression and continuing to decline throughout the 1980s and 90s, consistently across socioeconomic groups (Putnam, 2000).

Putnam (2000) has faced perhaps the greatest criticism for his weak explanations of why social capital is in decline in the US and many other Western nations. The picture Putnam (2000) painted in Bowling Alone was one of generational disenchantment in which the baby boomers diverged from the path of social engagement, failing to participate as actively in civic life as preceding generations. Civic disengagement is attributed by Putnam (2000:283-4) to four primary sources: Ten percent of the decline is assigned to time and money pressures which constrain the ability of families to get involved in community activities. Confounding these time pressures and leading to geographical disenfranchisement are suburbanization, commuting, and urban sprawl which Putnam (2000) estimates has contributed to an additional ten percent of the decline. Field (2003) questions this conclusion on the basis that small towns have also experienced declines in social capital; evidence, however, does suggest that those who spend a large proportion of their day commuting tend to have fewer friends, and lower levels of formal social involvement, they also have lower levels of personal happiness and happiness with their community (Williamson 2002).

Putnam (2000) attributes some of the greatest changes in social involvement to the advent of electronic media particularly the television which, he believes, inhibits social interaction. Those who spend copious amounts of time watching television are ‘isolated, passive and detached from their communities’ and have less time for social interaction

(Fukayama 1999), but Putnam (2000) does note that as yet we have not established whether these same individuals would behave differently in the absence of television, computer games and other electronic media. Putnam (2000:283-4) hypothesizes these forms of entertainment have contributed to roughly another twenty-five percent of the decline in social capital - figures brought into question by Hall (2002:34) who argues that higher rates of social capital persist in Britain despite average levels of television viewing sitting at two and a half hours per day. Furthermore, those not raised on television in Britain are not significantly more likely to be civically engaged (Hall 2002).

> The apotheosis of these trends can be found most improbably, at the Holiday Bowling Lanes in New London, Connecticut. Mounted above each lane is a giant television screen displaying the evening's TV fare. Even on a full night of league play team members are no longer in lively conversation with one another about the day's events, public and private. Instead each stares silently at the screen while awaiting his or her turn. Even while bowling together, they are watching alone
>
> (Putnam, 2000:245).

What makes Putnam's discussion of the decline of social capital so interesting is the distinct generational element. A high level of civic engagement should have been instigated in the baby-boomer generation as they reached middle-age, but this engagement never happened and the subsequent generation, the X-ers, have exhibited even less social connection. It is clear that the baby-boomers were the beginning of a trend away from reading the newspaper, voting, church attending, volunteering and believing in their political influence (Putnam, 2000). Like other forms of social capital, religious involvement and its spin-off activities have been in decline. Putnam (2000:72) reports that active religious engagement was a part of 96 percent of baby-boomer lives as they grew up, but less than 60 percent are currently involved in religion. Putnam (2000:66) has found that roughly one half of all formal organizational memberships and philanthropic behaviours (such as volunteering) are facilitated by religion, raising concerns over the decline of religious involvement by approximately one quarter to a half of its former numbers. But amidst his detailed analysis of data illustrating a generational decline in social capital Putnam (2000) does little to explain why these generational effects are taking place. The current social capital abyss, Putnam (2000) asserts, is a result of the baby-boomers and generation Xers reaching adulthood, and cumulatively sucking the civic life out of society – but why? Deciding to watch television instead is a weak argument. It is clear that the baby-boomers were demographically unique and this raised a number of social impediments right from the age they started school as crowded schools meant less opportunity to learn social behaviours (Putnam 2000). The importance of this generational decline merits further investigation into the explanation of social learning which Putnam does not provide.

> ...almost all forms of civic engagement – from union membership to church attendance to petition signing to public meeting attendance – continued to plummet among young people who were in their twenties in the nineties – that is, Gen X'ers. In many respects, this generation accelerated the tendencies to individualism found among boomers, for X'ers are the second consecutive generation of free agents. X'ers have an extremely personal and individualistic view of politics. They came of age in an era that celebrated personal goods and private initiative over shared public concerns. Unlike boomers who were once engaged, X'ers have never made the connection to politics, so they emphasize the personal and private over the public and collective
>
> (Putnam, 2000:259).

The situation for social capital is different in Britain where levels appear not to have eroded in recent decades, and have even kept pace with educational attainment (Hall 2002). What has occurred, however, is that levels of social capital have diverged along social lines (Hall 2002). That the British experience is so different from the U.S. suggests that factors such as the growth of the welfare state and the role of women in society are not integral factors to the decline of social capital (Hall 2000). Perhaps, one could argue, there is a cultural element to the decline which leads some societies to become disengaged. But equally, should the tolerance which liberal societies also breed not contribute to the reproduction of bridging forms of social capital? Putnam (2000) puts great emphasis on the increased tolerance of Americans as having coincided with the decline of social capital but offers no further analysis than associating the experience with the broader trend of individualism.

The problem that we face in going forward in exploring social capital as a causative concept within society is its sheer complexity. The processes by which social capital is produced and reproduced are far from clear. What is clear is that there is a circular, self-fulfilling (or self-destructive) element to social capital – but with a process so deeply embedded within the framework of society it becomes very difficult to distinguish the impact that social capital has on a society from those of other deeply entrenched social processes, such as economic disadvantage. Howe and Shiell (2000:873) explain "Perhaps the most interesting feature of social capital, however, is that it does not depreciate with use in the same way as most physical assets. Instead there is a multiplier effect by which the more the stock of social capital is used the larger it becomes." If we do not know how social capital interacts with other social processes it becomes very difficult for us to understand how we can use it to begin addressing the plethora of social ills with which it has been negatively associated. A better understanding of how social capital functions would provide us with a clearer basis for identifying in what social context participatory research may be successful and what strategies we may adopt to enhance social capital throughout the research process.

4.3 SOCIAL CAPITAL & ITS PLACE IN SOCIAL THEORY

The concept of social capital is not without its critics or its politics. Social capital is rendered by some as caught in the discourse of neoliberalism where it falls under the ‘third way’ umbrella alongside volunteerism as a means of cost-free societal reform and as a basis for reducing spending on welfare (Mohan and Mohan, 2002; Whitehead and Didrechsen 2001). Meanwhile proponents of the political left see social capital as a tool through which political inequality is heightened as structures such as ‘old boys clubs’ work to the advantage of those with well established connections. There are many instances in which social capital has negative consequences for other individuals or groups within society. These generally take one of three forms (Onyx and Bullen, 2001): firstly, groups may foster social capital but use its strength for destructive purposes, such as the Ku Klux Clan and other violent groups; secondly, tightly-knit groups may focus their social capital inwards and exclude outsiders, a practice which is common in a number of social and professional circles – we need look no further than high school ‘cliques’ for an example of this; and thirdly, even the positive mobilization of social capital can have negative consequences when it comes at the expense of others (e.g., the mobilization of one group who gains funding for a project at the expense of another, less cohesive group). While these perspectives may be conflicting they share a common thread of attacking the way that social capital is used rather than the validity of the concept itself. Like many resources in society, social capital may be used to further the means of those already in power or to empower the disadvantaged; it is around this latter purpose that the proceeding discussion is framed.

Presently we have only a limited understanding of the way in which social capital is produced within groups, and even less knowledge of how the presence of social capital systematically impacts on wider society. Community-based participatory research bridges a number of these community building processes as group networks are fostered and social learning experienced. Bourdieu (1986, 1988) has integrated the concept of social capital into a broader conceptualization of the construction of civil society, and it is to him I will turn for critical insights into the role of social capital within society. Bourdieu's (1986) conceptualization of social capital is particularly useful as it is embedded in a framework which articulates the systemic nature of oppressive forces in society and is deemed by some to be the 'most theoretically coherent' understanding (Field 2003:17).

Bourdieu was amongst the first to bring the concept of social capital into popular use in recent years, albeit as an aside to his work's focus on economic capital and cultural capital.[20] Bourdieu portrays social capital in his 1986 work 'Distinction' as social relationships which contribute to the permeation of difference throughout society. For Bourdieu (1984, 1998) social difference is a relational concept he conceives of in a model of social space whereby individuals occupy distinct realities of economic and cultural capital: "For Bourdieu, then, social capital was really a superior form of mutual back-scratching and self-advancement. It was entirely positive for network members but served to bolster and reproduce inequalities in the wider world" (Whitehead and Diderichsen, 2001:76). These realities are a function of both the volume and type of capital possessed and are created by the process of distinguishing oneself from other socio-spatial positions (see Figure 4.1). The closer individuals are to each other in Bourdieu's model of social space the more they have in common. Similarities and differences borne out in space, are evident in one's social circles and voting patterns

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[20] Cultural capital is one's weight in areas such as education, consumption and recreation, it may be possessed in the form of objects, it may be embodied, and it may be institutionalized.

where the relative levels of one's cultural and economic capital determine the likelihood of whether one votes for the left or the right - or not at all we could add (Bourdieu, 1998).

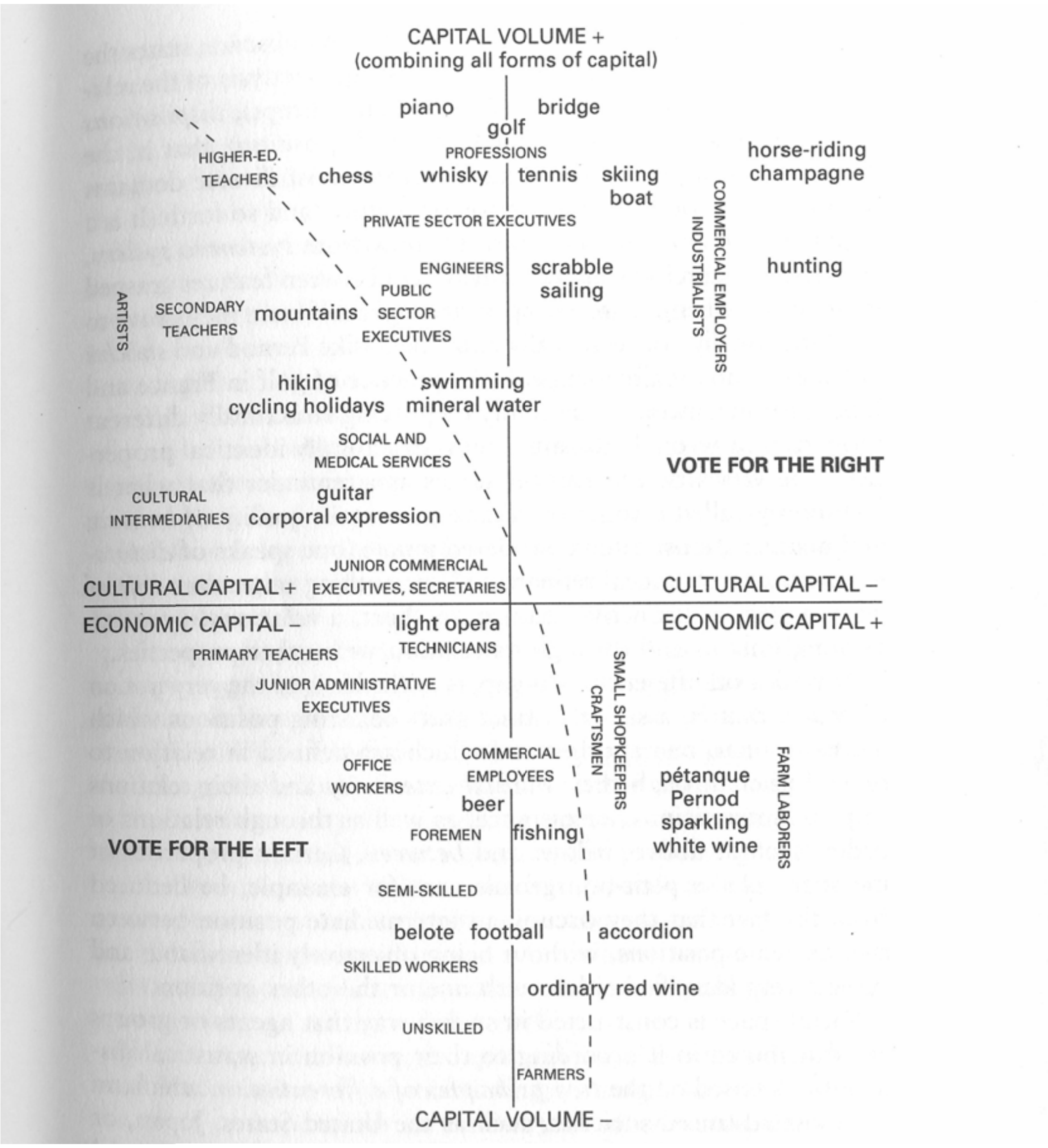

Figure 4.1: The Space of Social Positions and the Space of Lifestyles (the dotted line indicates probable orientation toward the right or left). (Bourdieu, 1998:5).

> Bourdieu’s concepts offer a way of understanding how the social is insinuated in the subjective, not in random idiosyncratic ways, but in ways that are socially structured and carry a history with them. Power can be understood as ‘capillary’, to use Foucault’s metaphor, but for Bourdieu the capillaries follow a pattern that can be apprehended and reflect ‘objective relations’, even if at some distance and in attenuated ways.
>
> (McLeod, 2005:26)

Habitus is the link connecting established tastes and preferences with the influence of society and in this respect we see the dynamic nature of human attitudes, but also acts of resistance. Bourdieu uses the term ‘genetic structuralism’ to describe the way in which structures inherent to the field are internalized by the habitus (Bourdieu 1991 in Siisiäinen, 2000). Habitus, rather than being a fixed set of influences, is in an ongoing dialogue with the field, and therefore is dynamic and reformatory in nature.

The determining impact of habitus on one’s behaviour has led to the inevitable labeling of Bourdieu’s work as structuralist, this is a label Bourdieu has forthrightly resisted. Bourdieu’s (1984) aversion to the application of structuralist thought to his work lies in a deeper discomfort with the use of dualisms in sociology for their reliance on “the opposition between the dominant and the dominated” (Bourdieu 1984:469). This critique is somewhat countered by Bourdieu’s (1998) suggestions that rather than being structuralist per se habitus is a ‘structuring structure’ that shapes the field, forming a reciprocal conditioning influence, with the field and habitus having a ‘productive and dynamic’ relationship (McLeod 2005). Bourdieu (1984:469) argues that dualisms form the basis of internal classifications of the social world and work to reproduce the distinction between the dominant and dominated classes, thus concreting pre-existing differences. Here we see an incompatibility with the work of Freire (1970) who draws on the dualism of the oppressed and oppressors to instigate social action.

Critics of Bourdieu's conceptualization of the social system argue that it is another form of structuralism in which the field and habitus reproduce social inequalities. Siisiäinen (2000) asserts that Bourdieu's work may be conceived of as structuralist, primarily because of the emphasis he places on symbolic capital which serves to restrict human agency by strengthening existing power dynamics. This position is likewise argued by Judith Butler (1999) who frames the habitus as a weak being, dominated by the authority of the field (McLeod, 2005). Butler sees no room for habitus to challenge the inscription of the field, or for an individual to inscribe the field with the functioning of their habitus.

While habitus is influenced by the field, as Butler (1999) argues, her understanding of habitus as powerless to influence the field is a little short-sighted. There may be a problem of collective efficacy at work here habitus being where societal influence meets individual preference, while the field is collectively shaped by society. One individual may find it difficult to influence an existing field but there are numerous examples of an entirely new field arising in response to a social movement such as feminism, or even the punk movement. In these instances, individuals align themselves by accepting and rejecting similar positions within a field and it is through collective action that social space is shaped (Bourdieu, 1990). Interestingly, social divisions such as communities and classes can thus be seen as socially constructed by the discourse which leads individuals to identify with a given group (Weininger 2005).

Bourdieu's conceptualization of social space is an embodied one; we see evidence of one's habitus in the way that one stands, speaks, behaves, and even how one thinks: "Habitus is formed through the embodied accumulation and effects of disposition (McLeod 2005:15)." The most developed aspect of Bourdieu's social analysis relates to the embodiment of taste evidenced by the everyday clothes we wear, or the car we drive.

For Bourdieu (1984), taste is the expression of one’s social space and leads individuals to work hard to either retain their position, or to transcend the boundaries of a field: “[Taste] functions as a sort of social orientation, a ‘sense of one’s place’ guiding the occupants of a given place in social space toward the social positions adjusted to their properties, and towards the practices of goods which befit the occupants of the position.” (Bourdieu, 1984:466)

Social capital, for Bourdieu, is highly tied to social position, it is a phenomenon that those high in economic and/or cultural capital will accumulate and use to maintain the social space they occupy. Altruism is one form of taste, as it is only viable where one’s habitus is predisposed to value this form of action. For us to carry out an altruistic behaviour it must in some way positively reinforce our conception of ourselves in terms of our position in society. We could even argue that the current popularity of the concept of social capital ,and its framing of the importance of civic engagement to the health of a community, is providing value to altruistic action. The social capital at one’s disposal, in Bourdieu’s (1986) view, is a function of the density of social networks and the level of capital available from each of those networks at any one time. In this respect, social capital is dependent on the other forms of capital Bourdieu favours – economic and cultural; Bourdieu (1998) uses the phrase ‘field of power’ to describe the social space that distinguishes those who hold a large amount of one type of capital from those who do not. He argues that networks of social capital are not an institutional or a social given, but inscribed through lasting relationships, which may be passed through generations (Bourdieu, 1986). In effect, Bourdieu (1998) argues that the maintenance of social capital depends on the continued reproduction of the family.

> One of the properties of dominant social fractions is that they have particularly extensive families ('great' families are big families) that are strongly integrated because they are united not only by the affinity between habitus but also by the solidarity of interests, that is, both by capital and for capital, economic capital, naturally, but also symbolic capital... and perhaps above all social capital (which can be shown to be the condition and the effect of successful management of the capital collectively possessed by the members of the domestic unit).
>
> Bourdieu (1998:71).

Where I disagree with Bourdieu (1988) is in his stating that social capital is a property that only those high in other forms of capital may possess. Admittedly, those with low levels of economic and cultural capital have fewer resources that may be traded, but the relative impact of social capital within impoverished networks may be as significant as for those trading social capital at a higher level: "Bourdieu really thought that social capital was an asset of the privileged and a means of maintaining their superiority. There was no place in his theory for the possibility that other, less privileged individuals and groups might also find benefit in their social ties." (Field, 2003:20) Social capital is seen by Bourdieu (1998) as a tool for inclusion and exclusion enabling the élite to uphold their place in society.

It is here we begin to see some important parallels with the work of Coleman (1988) and Bourdieu (1998) both of whom see social capital first as a primordial tool with direct benefits to the continued prosperity of the family line. Both authors also see social capital as tied to other forms of capital and, in this respect, it may be a tool for enhancing one's wealth and skills and for cementing one's symbolic place in society. The importance of social capital as a means of achieving community cohesion and political participation is of negligible interest to these authors. This may be why primordial relations are seen as so important, when we remove the significance of social capital to the common good of society we are left to view its importance to the individual – whose place in society is (arguably) shaped most significantly while under the direct influence of the family.

4.4 SUMMARY

In gaining an understanding of how inequalities are perpetuated in society, one may begin to see the potential for change not only in one's immediate environment but also in one's community (De Konig & Martin, 1996). Thus an initial step within the participatory research framework is to challenge the dominant ideologies by exploring a new perspective through which communities begin critically to view their oppressive environment. In Bourdieu's language, this means that we must transform one's habitus through a process that challenges one's conception of the social field they interact with to form their identity. In this way, participatory approaches involve recognition of the ways in which dominant actors and forms of knowledge render others subordinate (Cornwall, 1996:94). Essentially, Freire (1970) asserts that the oppressed must learn to view society critically in order for the realities of the structural oppression they experience in everyday life to become evident. In a sense the notion of 'performativity' comes into play as simple routines such as going to work condition the uncritical mind to accept and even justify one's position in society:

> Man's [sic] vocation realizes itself in his praxis, which transforms and expresses the world. In its turn, this praxis, with its action and language, turns back upon man and 'overdetermines' him; that is to say, it conditions him and defines the horizon of meanings within which his further action is to take place. Education – like all other processes of socialization – tends to reinforce this 'overdetermination.'
>
> (da Veiga Coutinho, 1970:vi)

Geography and social science research has predominantly relied on the specialized skills of the researcher to collect, analyze and interpret other people's realities (Hallet al., 1982). This has served to limit who is qualified to conduct research to the privileged élite, and has perpetuated a process whereby those in positions of power monopolise what should be researched and how it should be carried out. The power to use research to challenge structural inequalities has effectively remained in the hands of those who have benefited from the presence of inequalities through their privileged positions in society. The dominant research paradigms in geography and the social sciences have served to deny 'the knowledge generating abilities innate to every human being in the world' (Hall, Gillette and Tandon, 1982:24). Thus, when Kothari (2001:143) asserted "it is now widely acknowledged that the production and representation of knowledge is inseparable from the exercise of power" it became clear that it is academic knowledge, which has dominated research in the past and that the presence of positivist research paradigms have ensured it remains this way. Therefore, how can we place value on those paradigms that emphasize the need for distance between the participant and researcher in order to produce objective and impartial knowledge when it is these ideologies which have contributed to the concentration of power amongst only a few?

Bourdieu (1998) provides an anchoring for the concept of social capital in a framework of society that conceives of inequality as a dynamic, iterative concept vulnerable to the influence of social, economic, cultural, and symbolic processes. Participatory research practices challenge the norms of society by supporting research initiatives amongst those low in cultural capital, arguing that the skills and knowledge necessary to carry out research should not be restricted to those already in positions of power. Academics have the potential to extend their symbolic and social capital into communities to elucidate relationships of domination which are evident in the discourse of authority we frequently adopt (Weininger 2005): "What is at stake in the struggles about the meaning of the social world is power over the classificatory schemes and systems which are the basis of the representations of the groups and therefore of their mobilization and demobilization....” (Bourdieu, 1984:481) We must, Bourdieu (1984) argues, recognize that the discourse and schema we use is a product of our place in society, and the processes which work to cement that place.

Theorizing domination is no easy task and one can easily revert back to dualisms to distinguish the powerless from the powerful. This approach, however, overlooks the complex systems of society that shape the spectrum of social circumstances. The work of Freire (1970) is vulnerable for its oversimplification of society; it is this simplification that has also stood in the way of a rich understanding of the circumstances under which participatory research may be successful from emerging.

Chapter Five

The Limits of Community

> A community's ability to build its social capital is a measure of its vitality, its ability to govern, and its compassion toward its most vulnerable members.
>
> (Bouchard et al., 2006:S16).

Current research indicates that social capital is not evenly distributed across society; this is played out in lower levels of social engagement and trust amongst those of lower socio-economic status, divorced people, and people with lower levels of education (Fukuyama, 1995; Subramanian et al., 2003:42). Where social capital is low at the societal level, individual social capital also tends to be low suggesting that the social connectedness of an individual and their personal level of trust may be influencing not just their own participatory behaviours but also the participation of others (Lindstrom et al., 2002). In addition to the attitudes of individuals, (trusting or not), organizations and public infrastructure impact on levels of social engagement and societal trust inferring that community is important not just in terms of social relations but also place (Lindstrom et al., 2002). Our poor understanding of how communities 'produce' social capital necessitates that we further examine those circumstances under which social capital is successfully fostered.

Grounded in a geographic perspective this chapter will review place-based understandings of community and the implications for social capital as we look at the broader political context within which communities are located. Communities, in recent years, have been increasingly sandwiched in their position between the state and the economy as a new level of self-determinism has been hoisted upon the market and the rubric of governmental distance from the daily running of society has been espoused at all levels: “Communities can sometimes do what governments and markets fail to do because their members, but not outsiders, have crucial information about other members’ behaviours, capacities, and needs” (Bowles and Gintis 2000:5). By characterising community and situating the place of the voluntary or third sector in contemporary western society we may develop a better understanding of how communities produce social capital and whether we can assist communities in this production through such practices as participatory research.

This chapter intends to provide the reader with an understanding of how the spatial and social constructions of communities influence the wellbeing of residents. Key issues include social and ethnic diversity, the importance of place and the way in which governments and other institutions influence the fostering of social capital. As my doctoral research progressed and it became necessary to initiate multiple participatory research case studies with different groups in the study city, differing constructions of the ‘communities’ emerged as an influential factor in the success of the participatory research initiative. Of particular importance both to the research case studies and our understanding of community dynamics is the role of places in shaping communities and the importance of geographic location to uniting individuals in what may be deemed a community. Also explored in this chapter is the influence of social dynamics on the experience of social capital in neighbourhoods; the relationship between community characteristics and health status is examined; and the role of governments in shaping communities. First however, the relationship between diversity and community is discussed with a particular focus on stigma and the role it may play in alienating community members; an issue particularly pertinent to one of the case studies.

5.1 COMMUNITY & SOCIAL CAPITAL

The concept of “community” has been poorly defined in academic literature in the past as the disparate nature of the term stalled attempts to reach an inclusive definition (Day & Murdoch, 1993; Hall, 1986). Those carrying out community studies were criticised for applying an ‘enlarged social imagination’ to their work, particularly through idealized notions of communitarianism, and this led many geographers to distance themselves from the subject in the 1960s and 1970s (Phillips, 1998). A renewed criticism of the concept of community is waged by Herbert (2005) who, in a study of community policing, found citizens do not relate to ‘community’ as a mechanism for political engagement. This criticism of communitarianism has also been levelled at social capital due to theorists such as Coleman and Fukuyama who look toward social disruption as a cause for its decline (Whitehead and Diderichsen, 2001:119). These theorists are seen to idealise the communities of past decades overlooking the segregation and discrimination experienced during these periods.

The renewed focus on communities began in the 1990s as post-structuralists challenged assumed notions of community and came instead to view the term as a socio-cultural construct (Liepins, 2000). Current definitions of community tend to focus on the individual nature of the concept in terms of both the role of individuals shaping the discourse around community and the practices that produce the social connections inherent to community. Definitions of community vary substantially; Bowles and Gintis (2000:3), for example, define community as “a group of people who interact directly, frequently and in multi-faceted ways” while Liepins (2000:32) emphasises the importance of place in the manifestation of communities as “spaces and structures” that come to embody community through the actions and meanings people ascribe to them. The study adopts a definition of community as a cluster of individuals who share a common characteristic, whether it is a health condition or place of residence; community is also understood as a social construct grounded in material conditions and the cultural expressions of particular places and specific to each individual.

Because understandings of community may be idiosyncratic it is acknowledged that my use of the term ‘community’ is likely to differ from that of research stakeholders; for this reason during data collection stakeholder understandings of their community were sought as a reference point to frame their comments around their social lives and engagement. In line with Putnam’s beliefs in the importance of understanding ‘community’ its individual nature is discussed in greater depth within the concluding chapters: “A recognition of the importance of social capital in sustaining community life does not exempt us from the need to worry about how that ‘community’ is defined – who is inside and thus benefits from social capital and who is outside and does not” (Putnam, 2000:359).

5.1.1 Social Diversity

Social diversity has important implications for social capital and experiences of community. Research in the US has found that homogeneity (both ethnic and economic) is an important predictor of higher rates of social capital at the state as well as the neighbourhood level (Alesina and Ferrara, 2000). Alesina and Ferrara (2000:S48-9) suggest that “more homogenous communities have a higher level of social interaction leading to more social capital” whereas community involvement is lowest in ethnically diverse communities. Furthermore, heterogeneity has the strongest impact on community involvement when groups require high levels of social interaction and have a limited ability to exclude individuals (Alesina and Ferrara, 2000). It may be that communities have become more exclusive limiting access to ‘outsiders’ who may cease participating in a given activity (Wunthrow, 2002).

Intricately tied to any discussion of diversity are social values and the nature of social inclusion. Onyx and Bullen (2001)[21] have found that acceptance of diversity in society is highest amongst those with high degrees of agency and social trust. Social capital is particularly low amongst those who are opposed to racial integration (Alesina and Ferrara, 2000). The question of whether a community that illustrates high levels of social involvement yet limited tolerance for diversity can be said to have high social capital is posed by Woolcock and Narayan (2000). The authors follow up this quandary by arguing that while social capital is being created it is not being used for the purposes of the common good detracting from its value: “Our findings appear to confirm the distinction between bonding (within group) social capital and bridging (between group) social capital (Woolcock and Narayan, 2000).” Bonding social capital tends to be selective in nature, excluding those who differ from an individual or group. Bonding social capital may be used to cement the positions of individuals in a social hierarchy, whether they be privileged or in need. Bridging social capital, in contrast, crosses social divisions to encourage societal inclusiveness (Field, 2003).

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[21] Putnam (2000) asserts that he has not seen a single study which links social capital and social intolerance, and like social capital, Putnam attributes recent changes in tolerance largely to generational replacement.

The negative relationship between social capital and diversity is reflected on by Johnston and Soroka (2001) who suggest two reasons why social capital may erode diversity. The first, is the impact of community composition – individuals vary in their civic behaviour and the movement of less civic groups into civic neighbourhoods erodes social capital. A problem with this theory is that surely the opposite is also a valid scenario with socially engaged migrants increasing levels of social capital as they move into an area? The second theory relates to community context – increasingly heterogeneous communities may lead to the social withdrawal of already established groups who see their control and status within the community ebbing. A good neighbourhood is thus defined by Jacobs (1961) as one in which newcomers are readily absorbed.

The role of diversity in shaping community is a source of contention pitting Jacobs (1961) and others who argue for inclusive neighbourhoods against those such as Fukuyama (1999) who see sustainable communities as comprised of individuals for whom geographic co-location is just one aspect of the common ground they share. Fukuyama (1999) insists that a community is more than just a group of people, he argues that "true communities are bound together by the values, norms and experiences shared among their members. The deeper and more strongly held those common values are, the stronger the sense of community is" (Fukuyama, 1999:14). Alternately, a perception of exclusivity may make individuals reluctant to participate civically (Wunthrow, 2002).

While many authors argue that diversity does not assist in the fostering of social capital diversity in itself is unlikely to be a cause for its decline. In Canada we do not see a trend toward social capital declining in terms of cultural distance from traditional 'Canadian' values or ethnicities, or a direct correlation between the diversity of places and the levels of social capital (Johnston and Soroka, 2001). We must also be open to the possibility that communities excluded from mainstream Canadian society may develop their own networks which draw heavily from stocks of social capital but never have the opportunity to act in mainstream civil society. An example of this scenario is evident in work by Edmondson (2001) which identifies gender and sexuality advocates as amongst those 'civic cultures' who may be resisted by civil society yet still are able to contribute to the dynamism of a community indicating the presence of multiple 'civic cultures'. It may also be that traditional measures of social capital overlook culture-specific networks. (Johnston and Soroka, 2001).

5.1.2 Stigma, Diversity, & Community

Prejudice and discrimination have long affected the lives of individuals living with disabilities and many health conditions; amongst the most historically stigmatized being leprosy and AIDS. Effective community mobilization can result in increased allocation of health care resources and an emerging body of literature suggests that the experience of mobilization in itself can have positive health effects (see Campbell and Murray, 2004 and Hawe and Shiell, 2000 for discussions). While the relationship between social capital and general health is the subject of a growing body of literature, little attention has been paid to social capital amongst people living with specific health conditions; amongst the exceptions being findings by Ramirez-Valles et al. (2005) that community involvement may reduce the negative impact of stigma, depression and loneliness amongst Latino gay men in New York and Washington.

An important distinction must be made between stigma which functions within groups (self-stigma) and that which comes from outside (public stigma). Self stigma is particularly complex clearly having origins in experiences of public stigma and evident in feelings of disapproval focused against oneself (Ekeland and Cand, 2006). This may be a product of stigmatization within communities which produces a kind of hierarchy amongst individuals already marginalized from mainstream society (Gilmore and Somerville, 1994); this can be seen in the presence of 'layers' of stigma where those within a given group are discriminated against based upon relative levels of stigmatization. Amongst people living with HIV layered stigma is most evident in discrimination based upon a person's drug using status or sexual orientation (Reidpath and Chan, 2005).

Stigma can serve a range of purposes such as distancing oneself from a risk and may benefit the community who are discriminating argue Gilmore and Somerville (1994:1342): "...it can be a means of strengthening or homogenizing a community and its values by actually or metaphorically purging the community of unwanted, undesirable or unproductive traits" criminals being an example of this. The effects of stigmatization are felt in the reduced uptake of health and social services by people experiencing health-related stigma, and increased infections, for example among people with HIV, as the use of precautions may indicate the presence of disease (Gilmore and Somerville, 1994:1342). Gilmore and Somerville (1994) note that in some instances stigmatization can lead to empowerment as individuals react to discrimination by mobilizing against society or the disease/condition which is the face of their stigmatization. Bourdieu (1977, in Parker and Aggleton, 2003:18), however, argues that dominant societal grouping legitimizes hierarchial relationships through a process of 'symbolic violence' in which social and cultural tools are used to promote their own interests. The result is the legitimization of "the structures of social inequality (Parker and Aggleton, 2003:18). This process of differentiation posits some individuals to be less of a person than others in much the same way that feminists argue against patriarchy, disability health advocates have had to argue for stigmatized individuals to be seen as a whole person (Goffman, 1963, as cited in Wolch, 1989): “There appears to be little doubt that visible disabilities are commonly perceived as culturally unattractive traits which often bar the individual bearing such stigma from jobs, opportunities, other benefits, and personal relationships” (Wolch, 1989:385)

We are left with the question of whether prejudice and discrimination can be overcome through social capital which bridges different groups. In this respect, I am exploring whether approaches such as participatory research have the potential to reduce discrimination and experiences of otherness across groups. Woolcock and Narayan (2000) argue that communities high in bonding social capital but low in the bridging form, are not using their stocks of social capital in the interests of the broader common good. Fukuyama (1999) sees a heightened level of bonding social capital to be indicative of this era of increasing individualism where people are turning to groups where membership is flexible, the costs of involvement are relatively low, and individuals are like minded. The result is the development of increasingly compact communities without the benefits of multiple and diverse connections of the communities of the past and is consistent with the experiences of those people involved with the HIV/AIDS community in the study city (Fukayama 1999).

> Although observers have worried about the homogeneity, casualness, and self-interestedness of these [small] groups, research shows that members of small groups participate actively and over periods of at least several years, that they develop close affective bonds with other group members, that they discuss a wide range of issues (including civic and political issues), and that group members are more likely than average to be involved in other kinds of volunteer and community service activities, even taking account differences such as church attendance, age, education and gender. It is nevertheless worth considering the possibility that

> some kinds of small groups may be less conducive to this kind of community activity than others.
>
> (Wuthnow, 2002:97)

There are many instances of patient advocacy groups and disability rights organizations emerging in response to the stigma and oppression experienced by their members. The price of being associated with one of these groups, particularly where the health condition or disability is not immediately visible, may be stigmatization on the part of the public (Ekeland and Bergem, 2006). While Putnam (2000) has found that communities with higher levels of social capital are most tolerant of diversity, Onyx and Bullen's (2001) research found that those most at ease with diversity were most trusting, but they also reported higher levels of feeling safe, and greater social agency, rather than characteristics directly tied to social capital. From the point of view of communities, the more dense in number and diverse in nature networks of social resources are the better prepared they are to meet the needs of citizens (Wunthrow, 2002) and, we should add, the more tolerant the community is likely to be.

5.2 THE IMPORTANCE OF PLACE

Geographers have long emphasised the importance of place as a determinant of social, economic and health outcomes. Social capital theory offers one perspective for why these outcomes vary across space. Space facilitates the connections and capital amongst some social groups while serving to further isolate others; Bourdieu (1984) sees geographic space as socially ranked. In this sense the movements of individuals are structured as much by the social space within which they are located as their geographical distance from a site of capital (Bourdieu, 1984). This theory is borne out in research by Gatrell et al. (2004: 255) who have found that geographical proximity to capital alone is not enough to challenge social hierarchies: “mere co-location in geographical space does not mean that individuals have near-identical stocks of social and material capital.” Gatrell et al. (2004) suggest that we should focus more on individual social space rather than geographic space to gain insight into the relationship between the contexts within which we live and our health outcomes. Yet research to date suggests a strong correlation between location in geographical space and social behaviours; there is clearly more to ‘place’ than simply location, rather, there are social structures that influence our engagement with others and even our health and wellbeing.

Evidence of this relationship between social and physical space is seen in research carried out by Williamson (2002) who found high levels of political engagement amongst inner-city residents. Inner-city residents are more likely to vote, more likely to belong to a political organization, and more likely to attend political events such as marches than suburban residents. Inner-city dwellers, however, do not differ significantly in the number of friends they have or their community attitudes - suggesting that living in the inner-city fosters political engagement: “Perhaps more is at stake in the local politics of a large city compared to a suburb; perhaps a city has greater social and class conflict than a smaller place; perhaps the personalities associated with central-city politics are more compelling and more likely to be familiar to the public, not least because central-city politics is likely to dominate media coverage of local events in any metropolitan area” (Williamson, 2002:239). Alternate explanations may be that particular types of people interested in politics choose to live in the inner city.

If higher levels of political engagement are evident closer to sites of political action what is the experience within small towns where civic issues may also be closer to home? Community-oriented behaviour such as volunteering occurs at higher rates within small towns while those residing in the largest cities in the US are least likely to be civically active (Johnston, et al., 2005; Putnam, 2000). Big-city dwellers participate in: “10-15 percent fewer group memberships, attend 10-15 percent fewer club meetings, attend church about 10-20 percent less frequently, and are 30-40 percent less likely to serve as officers or committee members of local organizations or to attend public meetings on local affairs” (Putnam, 2000:205). Skinner (as cited in Hayes et al., 1999:190) explains that the civic behaviour of small communities is a result of those in power being more accessible and because they are affected by what goes on in their communities they are also more likely to contribute to social change.

It makes sense then that commuting is believed to severely erode both individual and neighbourhood stocks of social capital as neighbourhoods with lower numbers of occupants commuting tend to be more politically involved (Putnam, 2000; Williamson ,2002). This point is backed up by Putnam’s (2000:213) evidence that “each additional ten minutes in daily commuting time cuts involvement in community affairs by 10 percent.” Commuting is second only to education as the most important demographic factor affecting civic engagement; and it has a spill-over effect with high levels of commuting reducing civic involvement amongst non-commuters in a given neighbourhood according to Putnam (2000).

Putnam (2000) puts forth a strong argument that: “Place-based social capital is being supplanted by function-based social capital. We are withdrawing from those networks of reciprocity that once constituted our communities” (Putnam, 2000:184). This is concerning as it is everyday social interactions that are fundamental to the fostering of social norms. This is why rates of social capital tend to be higher in smaller, closed communities while large, anonymous communities decrease the likelihood of engagement (Putnam 2000). With the help of Jacobs (1961), Mohan and Mohan (2002), and Putnam (2000), we can conclude that there is a reciprocal relationship between the type of community one is a member of and the level of social connectivity experienced within that community. Those belonging to a heterogeneous, run-down, unsafe community are less likely to connect with their neighbours and thus stocks of social capital deplete further. Mohan and Mohan (2003:193) phrase this problem as a decline of generalized reciprocity which in turn leads to the blocking of channels for “coordination and communication” so that when community issues do arise there are no established means for their importance to be disseminated.

The city in which the present study is based is small in population yet is the major urban centre for the region meaning it does not suffer from the eroding effects of large commuter populations on stocks of social capital; nor does the city suffer from the problem of being large and anonymous. There is, however, significant economic diversity within the city with social and economic problems affecting the poorest populations; ethnically the city is very homogenous. So while the city overall is perceived as having a high level of social cohesion (Rosenberg, 2007) the social and economic diversity, according to the work of Mohan and Mohan (2002) and Putnam (2000), likely cause low levels of social capital within the more marginalized parts of the city. The economic polarization may work to exclude some groups from social engagement while those more economically advantaged occupy positions of power in local politics and social organizations.

5.2.1 Health, Place, & Social Capital

Communities play an important role in promoting health both by advocating for health care facilities and modelling healthy lifestyles. Social capital may contribute to the regulation of healthy behaviour in society, effectively reducing risky health behaviours through the practice of social control (Veenstra, 2001). Foucault (1976) discusses extensively the use of the moral imperative as a tool for ensuring behaviour adheres to healthy norms. This is a strategy adopted widely in public health in the promotion of breast feeding and cancer screening as advertising campaigns encourage friends and family members to act as health educators and to ensure others do what is implied to be 'best' for them (Lovell, 2002).

Health services are not distributed evenly through society. This injustice, which leads health services to be used at a higher rate and provided to a higher level amongst more privileged neighbourhoods, needs to be addressed in the context of community disempowerment (Gatrell et al., 2004). Under the rubric of social capital community relations are seen to impart benefits to society at an ecological level. Veenstra (2001) asserts that socially cohesive communities are likely to be more effective proponents to conserve levels of service provision in the face of budget cuts and may also be more effective at lobbying for additional services. The negative impacts of social capital are felt where social networks and associations are weak or unproductive as the relationships may be detrimental to both the contributing individuals and wider society (Schuller, 2001).

The social capital literature has built on the momentum of community empowerment as a means of resolving social problems particularly within the health field as community input in decision making has become revered as the most effective means of ensuring uptake and adherence within communities. Governments are increasingly looking to draw from the organizational capacity of communities to improve health status.[22] Communities provide opportunities for governance which, due to the social connections upon which they are founded, fill a space that eludes governments (Bowles and Gintis, 2000). The likelihood of local level solutions to emerging in response to problems, however, depends in large part on the connections and thus the extent of the social capital of individuals within that community meaning that models of community governance may simply reproduce inequalities (Johnston and Soroka, 2001; Onyx and Bullen 2001).

5.3 THE SOCIAL NEIGHBOURHOOD

The studies carried out by Bourdieu (1984) and Gatrell et al. (2004) led me to consider the relationship between social and geographic space and, specifically, whether our behaviours and decisions are influenced by our social interactions with our neighbours. It is already widely recognized that we behave in a similar manner to those with whom we share common socioeconomic and cultural traits but it is not clear whether these predate our social interactions or occur because of our interactions - although Bourdieu (1984) would most likely argue the two have a reciprocal relationship. An emerging body of research looks at this issue by exploring whether individuals behave in ways that are more similar to their neighbours than we would expect from their demographic backgrounds. Behavioural trends within neighbourhoods which cannot be explained by shared individual characteristics are viewed to be a function of the 'neighbourhood effect' which suggests that our views or behaviours have resonance with our neighbours.

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[22] This is evident in, for example, the introduction of Primary Health Care Organizations in New Zealand; health care groups which are legally required to involve lay community members in their management.

These relationships have significant implications for both the practice of gaining momentum within participatory research and working toward action in response to research findings. The participatory research process is founded on the theory that research may be an activist tool for freeing the most oppressed from the social structures which constrain them. The means by which behaviours and ideas spread through neighbourhoods has direct implications for the long-term success of participatory research.

Studies on the importance of neighbourhood effects have been slowed by the diverse explanations that abound as to how neighbourly relations are fostered. Johnston et al., (2005:1444) have identified five separate theories which might explain the similar values witnessed within neighbourhoods. Firstly, social interaction might be the means by which views and ideologies are conveyed with a homogenising outcome; secondly, it might be a matter of self-selection with individuals choosing to live amongst people with similar ideologies; thirdly, neighbourhood behaviour might be emulated based on observation; fourthly, individuals might hear about local issues and behave consistently with local interests; and fifthly, local pressure through canvassing etc. might influence behaviour.

Given that existing research has found the presence of neighbourhood effects beyond voting behaviours which are the focus of Johnston et al.'s (2005) research, we can assume that the fourth and final reasons are insufficient explanations of common behaviour and attitudes. The most compelling argument against neighbourhood effects is that their presence is a result of individuals choosing (or being forced through economic circumstance) to live amongst like people. Research in favour of the neighbourhood effects argument has found that levels of volunteering across the UK

(Davis-Smith, 1998, as cited in Mohan and Mohan, 2002), crime rates (Putnam and Goss, 2002) and voting patterns (Johnston et al., 2005) all occur at levels more similar within neighbourhoods than can be explained by the construction of the community: “Although the magnitude of the neighbourhood influence varies, scholars have been able to demonstrate that, over and above their individual predisposition to engage in risky behaviours, kids who live amid other risk-taking kids are more likely to fall into bad patterns” (Putnam, 2000:311). Significantly, Johnston et al., (2005) found those who were interacting most with their neighbours were more likely to vote for the political party preferred locally than more isolated people, suggesting that social interaction is the process through which norms are most effectively fostered at the neighbourhood level.

The finding that social interaction influences behaviour, particularly health-seeking behaviour, is a subject of criticism from Rissell (1994) who argues that sense of community and community capacity already are amongst long established community determinants of health. Rissell (1994:39) states that it is through community empowerment that health promotion has been an effective tool as it draws from community participation and representation, but notes: “... little consensus exists regarding exactly what is meant by the empowerment of local people, or which community networks and relationships are most likely to promote this empowerment, despite the fact that this is the key goal of most community-based health promotion programmes.” Similar sentiments are voiced by Campbell (2000) who notes that empowerment is an important tool in health promotion not because individuals learn more, per se, but by having control over the health promotion process, and thus their lives, means that individuals will feel more in control of their health. Social isolation, in contrast, has clear negative effects on health. The duration of this debate is evidenced by Durkeheim’s work on suicide (1897, as cited in Field, 2003) which found that single people and members of less cohesive communities were more likely to commit suicide. Similarly those with deeper social ties have been found to live longer than those with weaker social networks (Whitehead and Diderichsen, 2001).

5.4 SOCIAL CAPITAL & GOVERNANCE

Social capital influences societal attitudes toward government but equally government may influence social capital within society. This section examines the conflicting views in the relationship between governments and the fostering of social capital. Research has indicated that those who express and exhibit norms of trust and reciprocity within their community are also likely to extend these views to the government. Johnston and Soroka (2001) see trust to be an important psychological component of social capital which is first invested in other citizens, followed by institutions and communities. Social capital, for example, is the only characteristic at the aggregate level which is associated with honesty when paying one’s taxes (Putnam, 1990). Those who see their peers as likely to cheat and distrust the government are themselves more likely to cheat and distrust the government. This leads Putnam (1990) to argue that in communities where individuals pay their taxes and place trust in the government, the citizenry are more likely to take ownership of the infrastructure. Communities with high levels of social capital are more likely to believe that the system works, and thus think of society, and indeed the government, in terms of ‘we’ (Putnam, 1990). The opposite occurs in communities with low levels of social capital; the government becomes a ‘they’ from whom gaining economically (e.g., by cheating on taxes) is seen to be more acceptable.

In the US research suggests that institutionalised trust is declining at the same, if not a faster rate, than generalised trust (Putnam, 2000). Coleman (1990) draws attention to the elevated number of malpractice suits filed every year in the US reflecting a breakdown of trust between the medical establishment and the general population. Historically, physicians have occupied an elevated position in society and challenging a doctor's authority was rare (Coleman, 1990:308). The spin-off effects of this specific decline in social capital have included higher costs for medical treatment (due to the increased cost of insurance), the reduced availability of medical services, and even the refusal of some obstetricians to take lawyers and lawyer's spouses on as patients. In explaining why malpractice suits have increased so markedly in the US, Coleman's (1990) description is lengthy, but a useful illustration of the different dynamics – social, institutional, and economic – which affect social capital:

> ...several factors have changed. One is that physicians' monopoly on medical knowledge has been lessened by an expansion of education. A second is a reduction in the likelihood that there is a personal relation between physician and patient, since a patient is less likely to use a family doctor or even a general practitioner and more likely to see specialists for particular medical problems. A third is the high income of many physicians which reduces the perceived asymmetry between services and compensation. A fourth is the increased use of liability insurance, which transfers the financial cost of a lawsuit from physician to insurer.
>
> (Coleman, 1990:308-9)

5.4.1 The Role of Government in Putnam's Work

As Putnam's initial research focus the government plays an important role in the production and destruction of social capital. Putnam (1993) became aware of the importance of social capital to society when attempting to explain different experiences of governance across northern and southern Italy. Putnam was interested in the level of public participation in government, driven by an assumption that: "A good democratic government not only considers the demands of its citizenry (that is, is responsive), but also acts efficaciously upon these demands." (Putnam, 1993:63) Once Putnam (1993) had established that the performance of regional governments in Italy were not associated with the levels of funding they were receiving he began to look into social explanations for poor governance. Putnam's (1993) research painted a divisive picture; in the south the government was seen to be unresponsive to its citizens who were mutually disinterested in politics seeing politicians as useful in meeting their individual needs, such as finding a job, but rarely becoming engaged at the community level. The contrasting image of politicians in northern Italy - where communities were politically and socially engaged and politicians were seen to be effective - produced Putnam's understanding of social capital as the "features of social organization, such as trust, norms, and networks that can improve the efficiency of society by facilitating coordinated actions" (Putnam, 1993:167), an understanding differing from the present in its failure to recognize the transfer of resources as the central feature of social capital and the structures of society as facilitating its transfer.

Where ideals of trust and reciprocation were being practiced in Italy instances of opportunism and deviation from norms were greatly reduced. Putnam (1993) found that in civic communities, where political and voluntary involvement was high, individuals had greater belief that their fellow citizens were likely to behave in a law-abiding and respectful manner whereas in areas where crime rates are high and economic insecurity prevalent, trust was negatively impacted (Fukuyama, 1999). As Putnam (1993:111) argues: "In the less civic regions nearly everyone expects everyone else to violate the rules. It seems foolish to obey the traffic laws or the tax code or the welfare rules, if you expect everyone else to cheat." In regions with high levels of social capital cooperation is less problematic as individuals are more confident that others will not act simply in their own self-interest (Putnam, 1993).

The possibility that looser policing and legal processes to counter socially disruptive behaviour have contributed to declines in social capital is posed by Fukuyama (1999). This reasoning suggests rather than pulling out from social involvement and increasing the role of the state in the production of norms may increase social capital. For example, through the decriminalization of homelessness and failure to prosecute for graffiti the civil rights of citizens were being respected at the cost of tolerating social disorder.

5.4.2 Government Social Support

Putnam's (1993) early work in Italy set the conceptual stage for social capital to become a political pawn with the political right arguing that the growth of the welfare state has displaced social capital. The broad argument made is that increased social spending fosters independence from the social connections which would form a financial safety net were the government not available as provider. Paraphrasing Coleman (1990:306), this decreases the number of social credits an individual may have outstanding at any one time, which reduces the instances in which cooperation with others is likely to be sought. Undermining this argument is research by Hall (2002) and Rothstein (2002) which has found relatively high levels of social capital have been sustained in Britain[23] and Sweden[24] despite the growth of the welfare state since the 1950s. Rothstein (2002:323) goes so far as to state: "In fact, if one looks very closely, leading theorists of civil society agree that general welfare programs cannot be seen as subversive of civil society". Furthermore, the weaker association between family disruption and social disorder in Europe (as compared with the US) leads Fukuyama (1999) to hypothesize

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[23] Social capital is measured by Hall (2002) through associational membership and political engagement.

[24] Rothstein (2002) hypothesizes that the universal nature of Sweden's welfare system may have ameoliorated any potential declines in social trust as those receiving benefits may in fact be quite wealthy.

that the more supportive welfare state of these European countries is part of the reason levels of social capital have not declined. If the welfare state were impacting on levels of social capital, all we would need to do is adopt conservative social values and diminish state spending on the assumption that individuals would draw instead from their social connections with positive implications for community social capital. Putnam (1993) reminds us that liberal ideologies tend to be aligned with individualism and reducing one's dependence on a community, the result being that individuals are more autonomous in their decisions, their actions, and their goals than ever before and there is greater potential to overlook or exploit an individual (Coleman, 1990).

5.4.3 Government & Social Control

Putnam (1993) argues that, in contrast to the left, the political right is more inclined toward a reduced role of the state in supporting individuals, with the community instead stepping in to support the individual. One of the shortcomings of governments and organisations with liberal ideals, according to Edmondson (2003) is the difficulty of moving from an ideological stance of supporting social values to a point of practical support in their messy contexts. The reproduction of social capital is intrinsically tied to the monitoring of civic norms, but these are norms we are loathe to enforce in a liberal society where freedom trumps all else. Indeed, surveillance as a form of social capital has historically been a solution to many common good problems, but tends to run counter to neoliberal ideologies (Edmondson, 2003).

> Both the Left and Right participated in this effort to free the individual from restrictive rules, but their points of emphasis tended to be different. To put it simply, the Left worried about lifestyles, and the Right worried about money. The former did not want traditional values to constrain unduly the choices of women, minorities, gays, the homeless, people accused of crimes, or any number of other groups marginalized by society. The Right, on the other hand, did not want communities putting constraints on what they could do with their property – or in the particular case of the United States, what they could do with their guns
>
> (Fukuyama, 1999:14).

Putnam and Goss (2002) override the argument many social capital theorists have engaged in over the role of governments in fostering social capital to provide explicit examples of how states, consciously or not, have supported its development. Specifically, mass public education, governmental consultation with public interest groups and tax subsidies for voluntary education are all means by which states have supported the development of social capital. The British government has been perhaps the most overt of Western governments in their pursuit of social capital, having developed a series of recommendations for building social capital that have been presented to the British Cabinet. These recommendations range from building new social networks for youth involved in crime, new methods of urban planning, and the promotion of volunteering in schools (Whitehead and Diderichsen, 2001:128). The argument in favour of this form of social engineering appears to be based on the assumption that norms form foundations upon which one must build and strategies such as clearing graffiti sends the message that norms are enforced within a given neighbourhood (Fukuyama, 1999).

The extent to which government policies that promote social capital resulting in meaningful, long-lasting change at the individual level remains to be seen. Putnam cautions us with assertions that social capital is still a function of trust, something which must develop in the social system independent of 'third-party enforcement' (Putnam, 1993:117); indeed Australian research suggests that there may be a disconnect between individuals and the government that serves them (Onyx and Bullen, 2001). Plenty of scholars are quick to critique government policies that do not promote social capital. Fukayama (1999) cites Kelling and Wilson's (1982) argument that were the police to invest greater resources in problems of social disorder individuals would feel better about the environment in which they live and thus it would be an investment in community capacity. Likewise, Fukayama (1999) argues, higher crime rates foster community distrust. "The fact that the American legal system's unwillingness to control low-level social disorder in the 1970s and 1980s contributed to the depletion of social capital, and the possibility that the advent of community policing helped restore it, suggests that public policy can have a role in either undermining communal values or helping to reinforce them" (Fukuyama, 1999:127). These forms of social policing do have significant draw-backs and raise questions surrounding the ethical practices of persecuting, for example, homelessness which, from another viewpoint, is a symptom of poverty.

5.4.4 Social Capital as a Tool to Address Inequality

Those in support of the government's role in fostering social capital argue that economic growth and social capital are deeply entwined and the government should be working to ensure that positive forms are being fostered, or work to prevent undesirable forms from being perpetuated as a component of its economic duty (Grootaert, 2001; Whitehead and Diderichsen, 2002). Accompanying this belief are those who see social capital as an equalising phenomenon and argue that the government has a role in ensuring equal access to resources. Putnam (2000) notes that many forms of social capital have come under fire by liberals concerned that they are advantaging some groups while disadvantaging others. The argument is that social capital is a tool which the government should be using to decrease the head start offered by social structures such as ‘old boy’s networks’ and instead facilitating growth amongst more marginalised communities. Indeed even Fukuyama who is wary of ‘excessive’ government intervention in the fostering of social capital suggests there may be a role for governments in limiting the economic domination of some groups (Whitehead and Diderichsen, 2001). Ostrom (1998) argues that the government has a role in resolving common good issues only if a country’s citizens are seen to be ‘helpless’: “If, however, one assumes individuals can draw on heuristics and norms to solve some problems and create new structural arrangements to solve others problems then the image of what a national government might do is somewhat different” (Ostrom, 1998:17). Thus for Ostrom (1998), the role of government is a function of the perceived agency and empowerment of individuals, a principle that somewhat correlates with the liberal practice of providing more to those socio-economically in need. The argument, however, becomes much messier when we try to define helplessness, and when we try to implement the concept.

While the arguments of the Right may be flawed, left-wing policies indicate that the other end of the political spectrum has done little to promote social capital in society. This valuing of individual rights and freedom of choice Fukuyama (1999) optimistically asserts is nothing to be concerned about as the cooperative nature of human beings will lead to the emergence of new morals and norms adapted to the new social climate: “The study of how order arises, not as the result of a top-down mandate by hierarchical authority, whether political or religious, but as the result of self-organization on the part of decentralized individuals, is one of the most interesting and important intellectual developments of our time” (Fukuyama, 1999:6).

The political Right blames the welfare state for the decline of social capital; the political Left warn that social capital is a concept used by the Right to justify the downloading of state services to the third sector. What neither of these perspectives tend to consider is the importance of social capital to the production of democracy and the running of public institutions (Putnam, 2000). There is a reciprocal process of engagement between social capital and government policy which is rarely commented on politically. The partnership of governments with the third sector to meet civil obligations the state is unable (or unwilling) to meet is but one example of social capital's intrinsic influence on democracy and an important factor where the government may not be trusted to provide a service (Whitehead and Diderichsen, 2001): "Second, policy decisions already have an impact on social capital.... Sometimes, though, policy decisions have the unintended side effect of eroding social capital, or even of creating perverse social capital (Whitehead and Diderichsen, 2001:121).

While social capital theorists rarely go so far as to espouse communities initiate a process of self-governance there is certainly a substantial argument emerging in favour of this approach. The devolving of governance to communities is predicted by Fukuyama (1999:6) who states this will be part of a larger movement toward civil monitoring of norms in reaction to the present technological age. Much of this discussion comes back to an issue of scale and the importance of political activity at the local level as a means of fostering engagement. Where individuals have the opportunity to act in the interests of the community and are positively reinforced for this (e.g., through the implementation of a policy lobbied for), they will continue to participate in a democracy 'by the people for the people' (Skinner, 1980:5). This form of local engagement is fundamental to achieving social change at the macro level (Onyx and Bullen, 2001).

There is more to social action at the local level than simply putting issues on the agenda. As has been discussed in previous chapters the process through which engagement is achieved is just as important as the outcomes. In this sense, governments, particularly neoliberal governments where the market has played a dominant role, have failed in their attempts to replace norms with social policy and have even eroded community governance (Bowles and Gintis, 2000). The third space, the voluntary sector, continues to play an important role in community governance, serving as a source of social connectivity bridging diversity and having a liberalising effect making us more tolerant of those who are different from ourselves (Putnam, 2000). Equally, volunteer organizations are places of surveillance where shared norms aid in facilitating their day-to-day operations by forging common ground and connections with the wider community (Bardhan, 1995, as cited in Grootaert, 2001). Stolle (2001) suggests that voluntary groups facilitate the establishment of trust through personal interactions and cooperative experiences which are later generalized to the wider society.

Those arguing against local government as vehicles for social participation adopt the perspective that the local is diminishing in importance; instead, they argue, we have developed a tendency to think big. Hall (2002), in particular, argues that the face-to-face, personal social capital which used to be drawn on to influence government policy has been forfeited in favour of use of the media. The role of social interaction becomes important for Hall (2002) only when local level action is necessary for social change and the media and government do not play a central role. This perspective, however, overlooks the grass-roots level social interaction necessary to establish a cause. While the media may facilitate a process of ‘jumping’ scale to achieve social awareness at a larger level than we would see through traditional social movements, the initial ground-level work must still be carried out to bridge differences and create networks of support at the local level.

5.4.5 The Canadian Government & Social Capital

The Canadian government's interest in social capital has been piqued in recent years by research suggesting it may be a useful tool for improving population health. The federal government's Policy Research Initiative for 2003 sets out an agenda to examine how these theoretical benefits of social capital can be translated into effective social policy (Health Canada, 2006). To do this they adopt a definition of social capital in which the concept is understood as: "the networks of social relations that may provide individuals and groups with access to resources (Health Canada, 2006:3)." To date this programme has found that Canada shares international experiences of a positive correlation between social capital and health and that the form of social network (specifically how large or small they are and what type of connections they constitute) have differing effects on different population groups (Health Canada, 2006).

Policy documents are quick to point out that social capital is already being fostered by the Canadian government in some forms through, for example, the support of social networks through various health programs (see, for example, Franke, 2006; Voyer, 2006). This does not mean that the creation of social capital is a goal of a given program but rather that by default through the fostering of social connecections that the building of social capital may be a spin-off effect. A series of priority areas for social capital policy are identified by Voyer (2006) a federal government representative, however, these priority areas appear to be more of a set of recommendations for local and provincial governments than an agenda for action at the federal level; the priorities are:

- Helping populations at risk of social exclusion: Individuals and groups who experience social exclusion are cut off from those social ties that would allow them to participate fully in the social, economic, and political life of their communities. They need connections built.
- Supporting major life-course transitions: Life-course transitions (e.g. labour market entry, divorce, retirement, loss of mobility) are high stress, high need times of uncertainty and instability. Although common to most people they are experienced with varying degrees of relative success. Individuals often need to turn to their existing social networks for support and assistance, or need to develop new social contacts to get the kinds of support and assistance required.
- Promoting community development efforts: Under a social capital perspective emphasis is placed on finding the most effective ways in which citizens, service delivery agencies, institutions and organizations interact and create linkages for developing sustainable changes in the living conditions and well-being of community members

(Voyer, 2006)

Unlike their British counterparts the Canadian government is presently enacting only studies of the phenomenon of social capital and appears unlikely to follow in the footsteps of the New Labour's recent strategies for building social capital and cohesion through means such as giving tickets for anti-social behaviour. Rather, the Canadian government is investing in studying the concept further, particularly analysing existing Statistics Canada databases and carrying out surveys in addition to developing indicators to measure social capital outcomes in projects. On a practical level the government identifies support of the voluntary sector as an important means of fostering social networks (despite the fact that this support precedes current discussions of social capital) (Creasey, 2006). So while the Canadian government is openly exploring the *concept* of social capital as yet they are not looking at implementing policies that enhance its presence within communities.

5.5 SUMMARY

We have established that, deliberate or not, the state is integral to the production of social capital, and indeed, civic participation is central to the functioning of a democratic society. Moving to an ideology in which social capital is actively fostered by the government would require a sharp about-turn from the philosophies espoused by many neo-liberal governments. Policies which have aimed to increase individual autonomy, through means such as privacy laws, must make room for a discourse of communitarianism in which norms of civic cooperation are fostered by local networks. Counting against the state is a tradition of negative reinforcement as a means of controlling human behaviour. "Governmental and religious control is based mainly on the threat of punishment ('power') and noninstitutional practices are often of the same sort (Skinner, 1976:200)."[25]

There is much disagreement with regards to the present and future roles of governments in fostering social capital. It is clear, however, that governments have an impact on social capital whether purposively or inadvertently. The liberalisation of economies, and the increasing autonomy granted to individuals have all contributed to the erosion of social capital. What remains to be seen is whether government investments in social capital can make a difference. Community based participatory research for health represents a parallel practice to health promotion which draws on many of the same networks and strategies as government sponsored activities. In so far as the two practices aim to engage citizens and draw on resources of social capital for change participatory researchers may draw from the lessons learned by governments. The Canadian

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[25] Positive reinforcers, in contrast, usually gain their value through their associations, for example, money allows us to make or obtain the things we want, and social contact provides opportunities for others to make us feel good (Skinner, 1976:200).

government also in recent years has been investing in the health of communities through the funding of community-based research. This research will contribute to the emerging body of literature which explores whether social capital is being built through these practices.

Chapter Six

Study Methods & Implementation

> In the past few decades, a new paradigm of 'participatory' research has emerged, raising challenges to the positivist view of science, the construction and use of knowledge; the role of the researcher in engaging society, the role of agency and participation of the community, and the importance of power relations that permeate the research process and our capacity to become a just and more equitable society.
>
> (Wallerstein & Duran, 2003:27)

Emerging as a new research technique is participatory evaluation, the assessment of the participatory nature of collaborative research. These techniques address such issues as the influence of funding organizations on a research direction and divergent interests of research stakeholders and their community building partners. In designing the research methods for the present study I initially drew from some of those participatory evaluation tools pairing them with more intensive qualitative methods. As the research process developed and stakeholders turned over it became apparent that these, more rigid, processes of evaluation did not meet the needs of a small-scale, dynamic CBPR project. Instead, the participatory evaluation literature focuses primarily on health service environments and projects implemented at a larger scale than the current study.

Amongst the important lessons that were learnt from the participatory evaluation techniques was the value of basing evaluation strategies upon participatory ideals. Applying a participatory philosophy meant the data sources for the evaluation were more limited than originally anticipated but it prevented the participatory nature of the broader project from being undermined and counted stakeholder commitment to the evaluation process. Moreover, this study is strongly shaped by the methodological leanings of social geography – evident in the heavy use of qualitative methods for evaluation and particularly the use of feminist strategies for in-depth interviewing and the humanist traditions of participant observation. The emphasis on qualitative methods is indicative of a preoccupation with understanding the individual level experiences and perspectives of taking part in participatory research. Where the participatory evaluation literature did come into play is with the development of a questionnaire to measure the participatory nature of the project.

The current chapter is concerned with reviewing the research goals and discussing the methods which were used to achieve those goals. I discuss the practice of evaluating the participatory research case studies, the process of gaining ethical approval and the way in which the methods evolved as the project went on. The chapter concludes with a discussion of where I stand in relation to the research and stakeholders in the participatory process drawing from feminist traditions of positionality.

6.1 IMPLEMENTING PARTICIPATORY RESEARCH

> Making the decision to try participatory research was doing things backwards. Standard research textbooks advise social scientists to first identify a research problem and then select an appropriate method. Instead I had an approach in search of a problem.
>
> (Maguire, 1982:111).

My decision to adopt a participatory research approach arose both out of a desire to be involved in research with social pertinence and an interest in exploring alternative approaches to knowledge production. While conducting interviews and working with the results of my master's thesis I became acutely aware of how one-directional the relationship is between the stakeholders and researcher within the bulk of traditional research. Feminist methodologies suggest that the interview process should be an empowering experience for the participant as the researcher is valuing and validating the participant's perspectives; however, I believe this approach does not promote a particularly deep level of empowerment and commitment to the participant. In CBPR, the researcher becomes a partner in the production of research, one who works with communities to solve problems and achieve collective action (Park, 1993). At the very least, a participatory approach allows community members contact and support with people in shared circumstances with personal growth potentially resulting from such contacts. Ideally, the participatory approach also results in the successful production of research in which stakeholders gain the knowledge and skills to overcome sources of oppression in their environment.

The collaborative nature of participatory research creates many incompatibilities with traditional academic research processes as the researcher, in favouring community needs over the achievement of academic interests, does not have control over the direction that the research will follow (Heaney, 1993). Participatory research sits uncomfortably next to dominant research paradigms in the social sciences as its collaborative nature produces results which cannot be easily assigned to any one individual. The researcher is unable to define clearly their input into the process or claim authorship over publications, thereby negating the academic definition of a successful researcher, more so where a doctorate is concerned as PhD requirements clearly state the need for research to be owned by and attributed to one individual who is being evaluated on his/her ability – not a community's - to produce research (Heaney, 1993). Participatory research can be evaluated in terms of research outputs, the achievement of social change, or the sense of empowerment gained by stakeholders. None of these evaluations, however, can be directly attributed back to the researcher, as this would suggest the research process had not been collaborative which in turn would be a participatory failure! The question then arises as to how one can meet the requirements of a PhD to contribute new knowledge to a field when the research process cannot be controlled or the data claimed as one's own?

6.1.1 The Tensions of Facilitating Participatory Research

Positivist research places the researcher firmly in the position of investigator whether it is through the practice of sourcing information from journals or analyzing data. Feminist researchers were amongst the first to problematize the notion of the researcher's impartiality and objectivity. This process of questioning has led to the emergence of more self-aware practices of conducting research with the goal of overcoming power imbalances between the researcher and participant. Feminist researchers have discussed in-depth the tensions of carrying out qualitative research and the alternate skills which one needs to develop in order to be flexible, responsive, and most of all sensitive while collecting data (Davidson, 2001; Gibson-Graham, 1994).

As both facilitator and evaluator of the participatory research process my relationship with the CBPR project is complex yet reflects a necessity that the evaluation be identified as my own work. To account for this complex relationship the research questions are designed such that the goals of my thesis are not contingent on the success of the participatory process. While my effectiveness as facilitator is likely to influence the success of the participatory venture this is not a factor that the success of my PhD was expressly contingent upon and I made this clear to the collaborating community. I explained that while I was working toward the same positive outcomes as them, my ability as a research facilitator and the success of the project was not what my PhD hinged on. It was hoped that by making this explicit community members would not hesitate to express their true opinions.

There is no easy resolution to the tensions inherent to the multiple roles of the researcher in participatory research and the conflicted positions of the stakeholders. Practicing feminist strategies of positionality and reflexivity make explicit the forces acting on researchers and in making the research process transparent may in fact enhance the quality of research being produced. While the process of reflexivity in itself as a resolution to these tensions is not entirely satisfactory in my own mind I am inclined to see this as due to an ingrained positivist belief that the researcher must be distanced from the project at hand to uncover the 'truth.' Being comfortable with the fact that participatory research is never going to be neat and may produce multiple, conflicting perspectives may be the first step in evaluating the process.

The conflicting roles of the researcher may present tensions throughout the research process and most certainly within academia where notions of objectivity and impartiality are no longer illusions. But does this identity conflict have implications broader than simply academia? If we are to heed Wallerstein's (2004:10) words the answer would be yes - the disinterestedness and the qualifications of the researcher are central factors in the public's ability to place trust in the scientific community: "We assume that specialized knowledge is difficult to acquire, demanding long and rigorous apprenticeship. We put our faith in formal institutions, which in turn are evaluated by reliability scales.... In short, we trust that professionals have appropriate skills, and most particularly the skill to evaluate new truth claims in their fields...” If we encourage lay community members to carry out research are we undermining future opportunities for ourselves to carry out research? The conflicting roles of the researcher in CBPR has implications both for the current research and beyond; these implications are a significant theme connecting the remainder of the thesis.

6.2 THE RESEARCH GOALS

The effectiveness of participatory research refers broadly to its success as an alternative to mainstream research strategies. Of particular interest are positive experiences which indicate that participant involvement leads to a wider investment in a community’s social capital. Social capital, however, is a complex, dynamic concept which is difficult to pin down. Onyx and Bullen (2001) specifically note that while an individual score of social capital can be produced (e.g., through survey measures), we must first understand the messy context of social capital within the nuanced setting of each community. Furthermore, studies of health and community have been vulnerable to underdeveloped notions of what positive forms of social capital consist of leading to an erosion of their applicability (Campbell, 2000).

To establish the effectiveness of participatory research I draw primarily from participant observation to reflect on how the process unfolded in the case studies. The participatory experience is portrayed ethnographically with support from focus group discussions and interviews with stakeholders producing an emerging narrative. The thesis focus is on the challenges involved with participatory research and the costs and benefits which result;

and particularly whether CBPR is an approach appropriate to widespread adoption within academia. The specific research questions are revisited below:

a) Does the process of ‘conscientization’ , as advocated by Freire (1970) really occur in participatory research?

b) Can the goal of collaborative research be realistically achieved throughout all aspects of the research process?

c) Does the participatory process result in useful learning for both the researcher and the community stakeholders?

d) How compatible is the role of academic researcher with that of CBPR facilitator/activist?

2. These overriding research questions will also be drawn on to assess how useful participatory research is to the sub-discipline of health geography. Specifically, I am interested in:

a) Whether employing CBPR may enrich existing knowledge in the realm of health geography.

b) What are the difficulties of applying participatory research to health geography, particularly within the context of academia?

6.3 METHODS OF ASSESSING THE PARTICIPATORY PROCESS

To achieve the thesis goals participatory research case studies were implemented in health-, disability-, and ageing-related settings. Chapter Seven discusses the nature of these case studies whereas the current chapter is concerned with the process of evaluating these case studies. Here I detail the means of data collection employed and connect the goals of the thesis with the methods drawn upon.

Three case studies were ultimately initiated over the course of the study. The first case study, with people living with HIV/AIDS, involved intensive effort to recruit participatory research stakeholders with no success; instead a series of interviews were carried out with community members and the barriers to participation discussed, see Chapter Eight for further detail. The second case study, with a disability-focused organization, faced managerial barriers and did not get started. The third, and final, case study was carried out with a group of social housing residents. This case study was successfully initiated with research stakeholders recruited, participant observation, and interviews carried out. This group initiated their own CBPR project, collaborated to produce research, and worked to raise awareness of the project focus in the wider community. This case study is discussed in-depth in Chapters Eight, Nine, and Ten. See Figure 6.1 for a diagram depicting the levels achieved within the various case studies.

To evaluate the effectiveness of community-based participatory research a mixed methodology was initially proposed with an emphasis on qualitative methods. Participant observation, interviews, and focus-group discussions were drawn upon to enable an understanding of participants' values, emotions, and intentions, factors which can rarely be tapped into using quantitative methods (Winchester, 2000). Qualitative methods allow experiences to be explored in-depth and in a context which quantitative methods do not allow. The competing needs for detailed narrative and anonymous feedback led to the mixed methodology research design. The employment of quantitative and qualitative methods is carried out to enable a more detailed narrative to arise through the comparison of multiple data sources. This practice, termed triangulation,

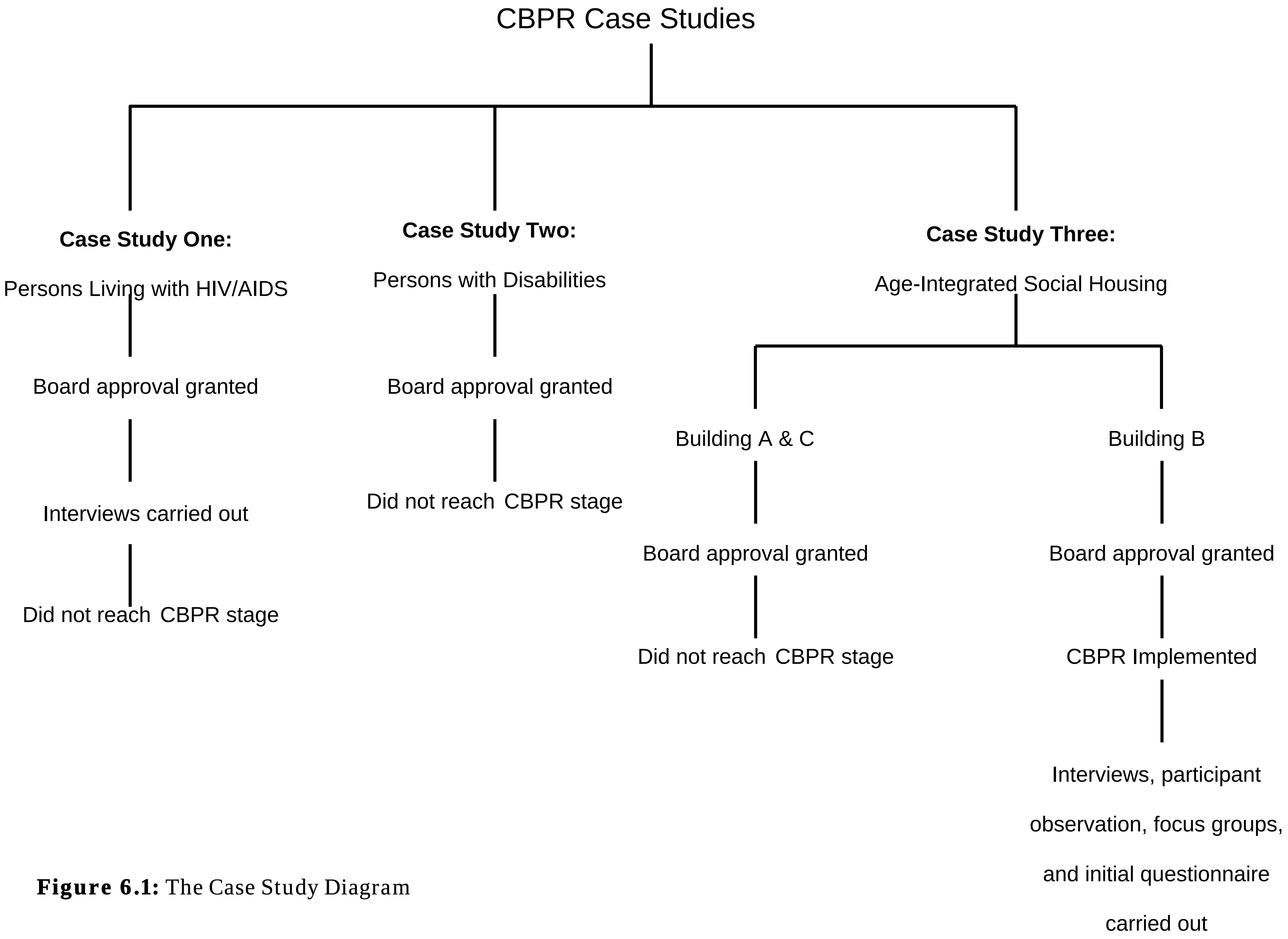

Figure 6.1: The Case Study Diagram

enhances the understanding of study questions and increases the level of rigour in research by allowing inconsistencies in stakeholder responses to emerge (Limb and Dwyer, 2001). The quantitative methods, however, proved unsuitable for the present study and are not discussed elsewhere.

6.3.1 Research Approval

The initial research plan was to carry out one case study with people living with HIV/AIDS. Ethics approval from the General Research Ethics Board (GREB) at Queen's University was initially sought and approved in July of 2005. Application of the proposed research strategy to recruit individuals led to an exceptionally low response rate; as a result in November of 2005 to improve the response rate, a process of interviewing individuals was proposed to GREB as an amendment to the original research protocol and was approved. While a number of interviews were carried out in October of 2005 the continued lack of interest led me to seek the establishment of a participatory research project with other groups in the same study city. On the advice of the departmental research ethics coordinator I did not seek approval for this further change (i.e., changing the number of case study settings) as in all other respects, the procedures remained the same.

With a participatory research project underway in 2006, I was faced again with having to seek approval for changes to the research procedure as the research stakeholders were concerned with the amount of time and effort involved with the evaluation strategy I had initially proposed. With the support of the research stakeholders focus-group style discussions were proposed as an alternative to diaries as a source of data potentially as rich in detail and more acceptable to the stakeholders. These changes were sought and approved without any difficulty in November of 2006 (see Appendix 1 for the final version of all information sheets and consent forms).

While the fact that the research stakeholders were not willing to complete diaries was a disappointment from the point of view of collecting a range of data sources exploring both collective and individual views of the research, it indicated that the stakeholders were in positions of sufficient power whereby they felt comfortable resisting what would have been my imposition. My concern that conflicts may develop between stakeholders (which may be better aired in the diaries) was unfounded and while a consistent process of self-reflection on the part of stakeholders was missing from the final data collection the benefits to the participatory process outweighed the small cost of amending the evaluation procedure.

6.3.2 Participant Recruitment

In the context of the present study community members form the base of research ‘stakeholders’ with whose help the participatory project is designed and executed. Stakeholders are likely to be more engaged in the research activities and improve the quality of the research outcomes if they have an investment in the research, or will benefit from the research results (White et al., 2004). White et al. (2004) suggest that all community members who may benefit from the research, or be affected by it, should be invited as potential stakeholders. For this reason stakeholders were contacted through an umbrella organization, health, disability, or a housing non-profit. I aimed to draw as diverse a stakeholder base as possible into the project assisted by the fact that the stakeholders had the opportunity to invite other acquaintances to become involved.

It was expected that the ability of individuals to participate in the research would be affected by health status, available time and resource limitations (such as child care needs, and work demands) in addition to demographic, psychosocial barriers and a lack of interest in the research. Effort was made to overcome these barriers (e.g., by scheduling meetings at convenient times and sites and allowing for varying levels of commitment from those with limited time or energy to participate).

In some respects the term ‘community’ may prove to be a misnomer. Participatory research intends to provide all of those in a community with the opportunity to work toward overcoming issues that oppress them and the broader community; however, ultimately community representatives are likely to consist of only one small segment of that population. Concurrently there remains pressure on community members to participate in research, and “an implicit notion of deviance for those who choose not to participate.” (Kothari, 2001:148) In this respect I tried to ensure community members did not feel pressured into being involved by emphasising the voluntary nature of the research and the need for participants to be genuinely committed to the process.

A minimum number of ten stakeholders were initially identified as necessary for the CBPR case studies to function. When difficulties attracting participants into the research process became apparent this number was reduced to six with the acknowledgement that significantly more commitment would be required from a smaller group of people.

6.3.3 Participant Observation

> Participant observation is a technique that involves living, working or spending periods of time in a particular ‘community’ in order to understand people’s experiences in the context of their everyday lives.... The advantage of participant

> observation is that it produces rich detail and description (especially non-verbal information) about people in the context of their everyday lives.... Whereas an interview provides information from only one person’s perspective, participant observation enables the researcher to gain a broader perspective or overview of a ‘community’ and the relationships within it.
>
> (Limb and Dwyer, 2001:44)

Participant observation provides descriptive context-specific information which allows the nuances of everyday interactions and experiences to be recorded in a way that the more structured methods of interviewing and survey data do not. As Limb and Dwyer (2001) describe above the ability to both observe and participate in the social context of a group allows for a better sense of the ‘community’ dynamic to emerge – something which a research evaluator coming in at the end of a project would be unable to tap in to. In part this speaks to a reduction of the insider/outsider distinction between the researcher and participants as the likelihood of ‘natural’ experiences taking place during participant observation is enhanced.

Kearns (2000) notes that there is a distinct lack of step-by-step instructions for carrying out participant observation. This deficit reflects the diverse connections researchers must make between what is being researched and themselves (Evans, 1988). Perhaps the most problematic decision the researcher is faced with regards what information is appropriate for including in the research and that has the potential to offend participants for its inclusion. This issue is described by Parr (1998:29) as a problem of the researcher’s gaze becoming covert as participants overlook their presence: “In highlighting subtle social moments, transient space and deeply personal geographies, it is not always possible to negotiate an open or overt researching role....” The ethical implications of covert observation were dealt with in the current study by ensuring research stakeholders viewed the study findings prior to the final printing thereby allowing any particularly sensitive information to be edited.

The argument is made by Parr (1998) for geographic ethnography to become more aware of the body and its often problematic role in the research and social relationship. While Parr’s (1998) work may be seen as nudging a fine line that exists between elucidating how social norms dictate bodily perceptions and objectifying the bodies of people with mental illness, she does highlight the way in which the body may be seen as a source of power in the research setting. In my own research, the fact that I was able bodied and most of my participants were not led them to focus more on describing their life experiences to me and served to engrain in myself the importance of accessibility whether it be in terms of seating arrangements or the publication of material in large fonts. I chose not to discuss the nature of the stakeholder’s bodies as the interview process allowed them to raise this as an issue themselves should they think it important to the research process.

Participant observation is drawn on to offer further insight into the process of participatory research, specifically, the goal of identifying whether collaborative research can be realistically achieved throughout the research process, the validity of the goal of co-learning, and the challenges of applying participatory research in the context of academia. Participant observation allowed me to keep a detailed record of how stakeholders participated in the research and what barriers to participation were identified. I was able to reflect on the research process and the nature of my involvement which ultimately improved my own performance as a facilitator by reflecting on how my involvement affected the research process.

Data collection during participant observation predominantly took the form of writing detailed field notes following a period of observation (taking notes during the observation may detract from the experience and make the researcher more conspicuous as an outsider). Keeping with tradition, I kept a field note journal to record the day-to-day experience of being involved with a group process including the negotiation of roles, instances of personal conflict, support, and general feelings toward the research process. The journal forms one of the bases of discussions surrounding the research process including describing the difficulties of achieving participation and the conflicting expectations I had to manage in my own role as facilitator.

6.3.4 Interviews

Interviews are widely acknowledged as a means of reducing the power imbalance which usually exists between the researcher and her 'subjects'. " [I]t is suggested that this type of research allows the development of a less exploitative and more egalitarian relationship between a researcher and her participants than is possible in other methodological frameworks" (McDowell, 1992:406). Primarily, however, interviews were selected as a method for the ability to interrogate in-depth the experiences and feelings of individuals involved in the participatory process. Interviews were carried out with people living with HIV/AIDS (with whom a CBPR project was not successfully initiated), and with social housing residents as a means of evaluating the CBPR project.

In-depth semi-structured interviews were planned with the stakeholders both prior to the commencement of the research and subsequent to its completion. The interviews conducted prior to the research were to provide a basis for understanding the major issues impacting on stakeholders' everyday lives. Co-learning is an important component of participatory research and the interviews were deemed an opportunity to jump-start this process thereby contributing to the understanding of the researcher going into the study. The interviews were also to provide a basis for discussing possible research foci for the participatory research initiative.

Interviews were carried out with six persons living with HIV/AIDS without the instigation of a participatory research project due to lack of interest. These interviews identified barriers to participation and important issues in their lives. With regards to social housing residents interviews were only carried out prior to the project with one stakeholder; this was due to the views of stakeholders that a set of initial interviews was not necessary. Interviews at the completion of the project were carried out with four individuals, two of whom were involved at the beginning of the project whereas five ceased regular involvement. Interviews at the completion of the project were an opportunity to reflect back on the process and discuss how (and if) personal understandings of the barriers in one's life had changed, the positive and negative experiences of the research process, overall feelings regarding one's involvement, and the project's success. Specific themes of the interviews were as follows:

- Personal understanding regarding difficulties in one's life, and whether perceptions of these difficulties had changed as a result of participatory research;
- What was learnt from involvement with the participatory research project;
- Personal satisfaction with the research outcomes;
- Perceived benefits of the research to the community at large;
- Discussions around individual benefits of the research versus personal cost in terms time and energy; and
- Changed community dynamics as a result of the project.

A number of strategies were used to promote a reciprocal relationship and encourage interview participants to feel comfortable. First and foremost, a semi-structured interview technique was adopted which ensured the key issues on my agenda were raised but also allowed participants to discuss issues important in their minds (Hay, 2000). In this respect, the interviews were somewhat emergent with new ideas pursued as a line of discussion frequently raising issues which had not occurred to myself as researcher. The result was interview transcripts rich in the context of the individual’s personal life and personal health conditions allowing their knowledge to be situated in a lived experience rather than taking a snapshot of their views as the questionnaires were intended to provide. A further strategy I applied in the final CBPR interviews was to begin by discussing what I had learned from the participatory research process thereby giving interview participants an understanding of what value I saw and making themselves more open to the interview process. This ability to share experiences and the context of learning from each other emphasized the value of the facilitator also being the evaluator of the research process and appeared to make interviewees more comfortable.

Interviews carried out with people living with HIV/AIDS were analysed using the software programme NVIVO a tool specifically designed to assist in the analysis of qualitative data. NVIVO assisted in the identification of emergent themes and organization of the data. I had initially planned to insert the ethnographic and remaining interview data into NVIVO as a means of making connections between the different data sources and to assist in the identification of new themes. I decided against this strategy during the course of the project when it became apparent how important the *process* was to achieving the research goals. Rather than insert my field notes into NVIVO I decided to use them as a basis for Chapter Nine as a means of allowing themes to be structured around the process rather than risk losing the importance of the process to the dominant themes. Later interviews were also coded using NVIVO; the primary means of analysing the interview material was to search for common themes which stakeholders brought up; however, pre-selected themes in-line with the research goals are also discussed in the results sections.

6.3.5 Focus Group Discussions

Focus groups were proposed as an alternative to community stakeholders keeping track of their thoughts in a journal. Reflecting the flexible nature of journal writing the focus groups were 5-10 minute discussions carried out at the end of a project meeting when stakeholders were already spontaneously beginning to discuss the research process. This strategy was used to build on a natural progression toward reflection and avoid feelings that the process was being forced or an imposition. It was also necessary to be flexible due to the unscheduled arrival of transport to collect stakeholders.

Focus groups are an effective means of enabling rich qualitative material through social interaction that may prompt discussions into areas and issues the researcher may never have thought of (Cameron, 2000). Focus group discussion were particularly well suited to the goals of this project as it enabled stakeholders to draw from each other and emphasise what they found important with the researcher having only a minimal role. In this instance I prompted stakeholders by asking broad questions, such as, ‘what do you think of our progress?’ And ‘why aren’t more people coming out to meetings?’ Discussions were recorded using an audio recorder and later transcribed.

The focus group material was often repetitive, perhaps speaking to the importance of the points the stakeholders rose, and was often supported in comments made by stakeholders at other points in the meetings or during telephone conversations. Once transcribed dominant themes were identified and categorized to reflect components of the research process. The focus group material appears within Chapter Nine where it provides an alternative voice to my own for discussing the research process.

6.3.6 Questionnaire

The final method proposed to assess the research process was questionnaires. Questionnaires were anticipated to be a means of gaining feedback in an anonymous manner allowing stakeholders to conceive of their levels of participation and knowledge gained on a standard continuum on which they may rank responses relatively. This quantitative feedback was to establish a general understanding of participation and form a basis for discussing in greater depth the nature of learning carried out through the research process.

The questionnaire used in the study (see Appendix 2) is a modified version of one developed by the Institute of Health Research (1995) entitled 'Guidelines and Categories for Classifying Participatory Research Projects in Health Promotion.' The questionnaire allows community participation to be assessed in all aspects of the research process, from identification of the research problem, through to issues surrounding authorship. The questionnaire was distributed to the research stakeholders to measure levels of participation they expected from the research process, and was to be distributed again at the end of the process to evaluate the level of participation that was achieved. This questionnaire was seen to deal with the nuances of implementing a small-scale participatory research project and was developed in Canada suggesting that language and phrasing was more likely to be appropriate to the stakeholders.

The initial questionnaire was distributed during one of the first research stakeholder meetings at a time when the stakeholders had committed to the research process and had a clear understanding of what participatory research means - but before any decisions had been made at the group level. The questionnaire proved to be of limited use due to substantial variation in responses amongst stakeholders and the fact that it represented only anticipated levels of participation and thus is a better indicator of the researcher's communication than of the participatory outcomes of the project (see Appendix 3). The follow-up questionnaires, to be distributed at the completion of the project, were intended to be compared anonymously to the respondents' expectations of the research process through a coding system. At the completion of the project, however, only two stakeholders who were instigators of the project were still regular participants. The lack of comparable data and the small number of stakeholders (four) remaining at the end of the project meant that re-distribution of the surveys would not be useful.

The inappropriateness of the survey method to the project evaluation is indicative of the unpredictable nature of CBPR. Despite the project beginning with a significant number of participating research stakeholders, attrition and the addition of new members meant the face of the group was very different and any attempt to compare expectations with realities would be meaningless.

6.3.7 Limitations to the Data Collection Processes

A number of difficulties establishing the participatory research process and changes to the evaluation strategy had implications for the data collection process. Data collection was based on the assumption that while some attrition of stakeholders was likely the group would remain largely the same. That there was so much turnover and so few stakeholders remaining at the completion of the project compromised the ability to gain meaningful quantitative data. As a result qualitative methods were relied upon as the sole data sources.

A final limitation to the data collection process was the lack of opportunity to discuss with the group how they felt about the research process. Meetings often felt rushed as we had so many issues to cover and the arrival of the disability bus and stakeholder's partners frequently meant that the meeting came to an end before reflections on the participatory process could take place. Compounding this was my awareness that the stakeholders were more interested in discussing the issue at hand and getting something done than discussing how they felt about participatory research. In this respect, it is very difficult to integrate participatory evaluation in a natural way – I became conscious that stakeholders might perceive me as being too pushy in pursuing my own research agenda.

6.4 POSITIONALITY

Nast (1994:57) reflects on the fact that our research interactions are always with 'others' leading us to see that "difference is an essential aspect of all social interactions that requires that we are always everywhere in between or negotiating the worlds of me and not-me." It is this 'betweenness' that necessitates we situate ourselves in relation to our research in order for the social relations and research processes to be understood by the observer. The notion that there may be a spectrum of otherness with those we share much in common at one end and those we diverge from socially in a multiplicity of ways is central to positioning our relative level of power and ease throughout the research interaction.

Entering into any participatory research process as a PhD student means bringing to a future relationship potential power imbalances in terms of educational achievements and, in most circumstances, a more privileged economic background. My experience in the present study was no different and led me to adopt strategies to reduce the social differences. At a very general level, I played down my status as a PhD student and instead portrayed myself as someone with technical (research) skills who would be helping the stakeholders out on a project of their choosing. I did this by referring to myself as a research associate with the non-profit agency I was working with or by describing myself more vaguely as a Queen's student which, while also having strong connotations in the local community, I hoped would not be as alienating as describing myself as a PhD student.

Aside from the educational distance between myself and the stakeholders there were clear generational differences and differences in my status as a (relatively) healthy, able-bodied individual. While I felt powerless to address the age difference between myself and many of the stakeholders, the fact that I was working with the stakeholders on health/disability issues meant that I had the opportunity to learn in great detail the various challenges in their day-to-day lives. In this respect the participatory research process assisted in overcoming the differences between the researcher and stakeholders – but only so far as the study issues were concerned. We spent little time socializing together and our meetings were predominantly taken up by discussions of health and disability issues. It was only in on-on-one situations that I began to feel the social distance was being bridged.

While the social distance between myself and the community stakeholders of the participatory research project is unlikely to have affected the evaluation of the project, I am sure that it did influence the participatory project in minor ways. Had I been more similar to the stakeholders in age and background there may have been more reciprocity in the research process and more ownership taken over the means of carrying out the research by the stakeholders. The fact that I had the stability of not being affected by chronic health problems and therefore was not in and out of hospital also made it easier for me to be the primary contact point for the recruitment of participants into the participatory project. This enhanced my position as controller of the research project – something which I did not want but for which there appeared to be very few alternatives. In this sense, despite my efforts to reduce the power imbalances these imbalances were, in fact, reinforced through the discrepancies in health status.

6.5 SUMMARY

Community-based participatory research is an innovative approach heavily promoted by those who practice it. There are, however, many critics of CBPR who argue that ideals of participation too frequently elude researchers who find their own priorities take over the focus of the research. This chapter has described a process of evaluating community-based participatory research to assess the extent to which ideals of participation and community empowerment can be attained when the approach is implemented in practice. Importantly, the focus of the thesis on the process of participatory research reduces the conflict which may otherwise occur between the researcher's interests and the interests of the community. The following chapters will discuss the practical experience of implementing CBPR while drawing from the participatory literature research to provide context and background for decisions made and protocols followed throughout the participatory process.

Chapter Seven

The Case Study Context

Research involving human subjects is rarely straightforward in part because of the complexity of human behaviour that we are seeking to understand. Amongst the challenges social researchers face is the recruitment of participants into a research project, a process which frequently requires the cooperation and support of an outside organization. Social science research must be understood in its broader context as shaped by the administrative bodies of academia including research ethics boards and thesis examination committees but also by outside organizations that have the power to facilitate, modify, or end research projects.

This chapter is concerned with establishing the social context for the three case studies by examining the nature of service provision within the study city as well as the social context within which the three case studies take place. This paints a background upon which the cooperating organizations may be better understood as well as the relative successes and failures of the three case studies. I discuss in-depth my experiences negotiating the administrative aspects of the three case studies and the challenges involved in developing working relationships with non-profits for whom the benefits of participating in a community-based participatory research project might not be immediately evident.

7.1 ESTABLISHING THE THREE CASE STUDIES

> Each community is cynical, suspicious and resistant to yet another research project being done in their neighbourhood. This is founded on the lack of control, an invasion of privacy to obtain services and the lack of any positive outcomes for children and families that has characterized virtually all previous research in these neighbourhoods.
>
> (Ontario, 1993 in Institute of Health Promotion Research, 1995:37)

Participatory research is rarely instigated by the community itself. Park (1993:9) suggests this failure to "spontaneously get together to analyze their own situation" and subsequently instigate community action stems from the inherent powerlessness of those Freire (1970) term the 'oppressed.' It becomes the role of the researcher in participatory research to act as the 'organizing force' in addressing the structural constraints acting on the lives of the community (Park, 1993). One of the paradoxes of participatory research is that so many studies are instigated by an outside researcher and the community group defined and brought together by the researcher, (Maguire, 1987), that the validity of the term 'community' is brought into question. Actively recruiting individual community members makes redundant ideals of communities in participatory research being 'natural social entities' arising to address inequalities (Cleaver, 2001:44). Working with an existing community organization as a gatekeeper may reduce the diversity amongst 'community' members and enhance levels of social cohesion.

Relying on people united by a formal organization to constitute a 'community' group creates its own biases and difficulties as the organization's contacts are unlikely to be representative of the community at large and the organization's involvement may influence the direction the research takes (Maguire, 1987). Sullivan et al., (2003) found that participants in her research frequently view local organizations, including women's and church groups, as valuable representatives of the community – but simultaneously driven by their own agenda. These agendas have the potential to supersede the needs of the community as a whole. To avoid becoming entwined with the politics of formal organizations, I sought the support of local non-profits to attract community members but resisted the involvement of employees or board members of that organization in the initial decision making within the participatory process. In practice, this relationship was not difficult to establish as the lack of funding for non-profits in the study city meant employees and volunteers rarely had the time available to get involved in extra activities. The non-profit organizations who participated in the study also understood the principles of the participatory research project and were comfortable not being actively involved.

With the support of three non-profit organizations, three case studies were initiated between 2005 and 2007. The nature of my relationships with these non-profits varied significantly. One organization I had been involved with on a volunteer basis and knew all of the staff. At the second organization, I knew one board member, and at the final organization I knew no one. I was careful to provide each organization with written details of the proposed research and the opportunity to discuss the logistics of carrying out the research prior to the study going forward for board approval. I was explicit with each organization that what I hoped for was access to the study population and the organization’s assurance that those who participated in the study would not be negatively impacted as a result of their involvement. The success of the participatory case studies was deemed to be dependent on the cooperation of these organizations as ‘gatekeepers’ to the communities who were to be the focus of the research. The process of gaining organizational buy-in was, in most part, successful though it was often a very drawn out and time consuming process in some instances; this is detailed below

7.1.2 The Study City

The study city, located in Ontario, Canada, is most marked for its strong regional presence as a medical and university centre. The city is home to a large number of institutions including universities, a college, hospitals, and a major provincial government facility. The combination of these institutions has created marked economic polarization within the city with large numbers of both professionals and low-income individuals. Income disparities have a strong geographic component with some parts of the city suffering significantly from relatively poor housing stock, high crime rates, and few employment options.

7.2 CASE STUDY ONE: PEOPLE LIVING WITH HIV/AIDS

The first case study focused on people living with HIV/AIDS. It represents a geographical diversification from previous research which focused on large North American, particularly West Coast cities (Brown 1997). Small Canadian cities are mainly overlooked in research on people living with HIV/AIDS due to the challenges of conducting research where those affected by the conditions number in the hundreds rather than thousands. The result is a gap in the literature leading to little understanding regarding how the social dynamics of living with HIV/AIDS in a small city impact on one’s life and the suitability of participatory research.

The AIDS movement across North America was undeniably successful in raising awareness of HIV/AIDS, reducing discrimination, pressuring governments to invest in AIDS resources and care, and promoting safe sex in the gay community (Brown, 1995; Chiotti and Joseph, 1995). While the AIDS movement in the early years was primarily initiated by gay men and their supporters, and thus concentrated geographically in the ‘gay’ districts of large cities, the gay agenda was often a source of discontent between those who saw HIV/AIDS to be the cause for activism and others who understood AIDS to be a significant issue within a broader agenda of social change countering homophobia (Geltmaker 1992). This disjuncture in ideology led to the splintering of many AIDS groups in pursuit of different means of carrying out activism and pursuing different priorities (see Geltmaker, 1992 for a record of this occurrence in the US). During the late 1980s, this movement was still largely a gay movement but as the 1990s progressed increasing numbers of heterosexual people began to be diagnosed with HIV. The changing demographics created pressure on organizations such as ACT UP (AIDS Coalition to Unleash Power) to modify the gay-oriented promotional material. Splinter organizations sprang up in response to this new need with many organizations responding to the needs of women who are physiologically and socially vulnerable to contracting HIV (Geltmaker, 1992).

Today in Canada hundreds of organizations devote all, or part, of their mandate to furthering the needs of people living with HIV/AIDS many with specific client groups such as working with youth, aboriginal peoples, and women living with HIV/AIDS. Surely this level of diversity, the very fact that HIV is increasingly affecting all groups in society should mean more tolerance, more funding, and more support for the needs of people affected? While this may be true, the diversifying of the disease presents more challenges for public health – socially, culturally, and geographically the disease is more diffuse than ever before causing social activism to be splintered in all number of directions and many of the unification campaigns, the awareness education, and even the calls for facilities are becoming outdated. These challenges are multiplied in small cities where resources are often fewer yet population needs remain diverse.

In the context of my research, the small size of the study city meant that only one non-profit organization and one local hospital are dedicated to serving the population living with HIV/AIDS. The non-profit organization provides social support and basic services for those living in the study city and nearby towns; being a regional service requires considerable financial and volunteer investment in transportation and services throughout the wider geographic region. I already had a relationship with this organization, having carried out an evaluation for them on a volunteer basis in the past, and it was through them that I contacted most participants and gained immeasurable support. The proposal I submitted to the Board of Directors was approved immediately, no doubt facilitated by my history of working with them, and I was given permission to go ahead with recruiting participants.

The HIV/AIDS non-profit was extremely supportive even throughout the tenure of a temporary Executive Director. The staff at the agency donated a considerable amount of time to assisting me with mail outs through the provision of client addresses, stamps, and even including a promotion of the study in a monthly newsletter they distribute. These initial promotion efforts were unfruitful with only members of a drug user support group attending a community meeting I organized. These individuals did not follow-up and contact me further. Instead, a series of interviews were carried out with service users living with HIV/AIDS to establish a sense of rapport, promote the study and, primarily, gain an understanding of important issues in their lives that could be the focus of a participatory project.

During November and December of 2005 I spent eight weeks at the social service agency as a means of gaining interviews with service users. Over this time, the community worker told clients about the study and introduced to me those who were interested. It was due to the continued support of the Executive Director that I pursued interviews with service users as a means of developing a rapport with service users, of understanding the barriers to developing a participatory research project, and for establishing participation in the CBPR project. In many respects, the extent of the support from the staff involved in this organization made it very difficult to end the project when it was not progressing as so many people had put in time to make it a success. As this project did not reach the participation stage, for reasons which will be discussed in Chapter Eight, it was necessary to establish case studies in other sectors.

7.3 CASE STUDY TWO: PERSONS WITH DISABILITIES

Interviews I carried out with people living with and affected by HIV/AIDS often raised concerns over the Ontario Disability Support Program as a primary source of income and the difficulties of participating in society when living with an episodic illness. This link, my own concern with disability issues, and the connection with a disability organization via a faculty member in the department led me to get involved with a local organization providing services and support for persons with disabilities.

As with the provision of HIV/AIDS services the study city is also a regional centre for disability services. A large part of the reason for this is the historical connection between institutions which led to the establishment of a psychiatric hospital in concert with the building of prisons. The city is presently home to the only rehabilitation hospital in the region and is the base through which most regional support for individuals with physical and intellectual disabilities are provided. The city is also home to a small number of non-profit organizations mandated to meet the needs of persons with disabilities through a variety of means. The disability organization I became involved with was one of these non-profits meeting the needs of individuals affected by a very broad range of disabilities.

Like the HIV/AIDS organization, the research proposal provided to the disability organization was accepted expeditiously by the board and anecdotally I heard that they were very enthusiastic about the project. Pinning down the Executive Director for a meeting did not prove to be quite as easy. After numerous unreturned phone calls and emails, the individual got in contact with me the day of the next board meeting, leading me to suspect that he was perhaps not as keen on the project as was the board. The meeting with the Executive Director and another staff member was very positive and I was provided with background reading on working with people with disabilities and we discussed the logistics of scheduling and promoting a community meeting.

The next stage involved the development of promotional material which I submitted to the Executive Director and the other staff member for approval within days of the initial meeting. The second staff member had been encouraged to get involved in the project by the board as a means of reducing the load on the Executive Director. Gaining no response to the emailed promotional material I made multiple phone calls which also went unreturned by the Executive Director. Finally, I contacted the other staff member who had been present at the meeting and she put me through to the Executive Director who agreed to phone me the following day once he had taken another look at the material. The phone call never came and I made the decision not to continue pursuing the project with that organization on the basis that its future success was already compromised by a lack of managerial support and might be further compromised if I continued to pursue the case study.

7.4 CASE STUDY THREE: AGE-INTEGRATED SOCIAL HOUSING

Connections between my supervisor and a local senior's organization facilitated the development of a project with the third organization. During an initial phone call with the organization's Executive Director, a study focused on age-integrated housing was proposed. These housing settings had become a focus of much of the Council's work over the past ten years as police calls escalated and, anecdotally, instances of drug use, prostitution, verbal abuse, and even violence against seniors had arisen in these housing settings. The Council had fought for many years for these social housing settings to revert back to their "seniors only" status but had come to the realization that they now should move forward by looking to improve relations between the senior and younger adult residents. The Executive Director suggested that implementing CBPR in these housing settings would be an ideal means of mediating relationships, addressing problems, and improving sense of community. From here we moved on with establishing a CBPR project.

Social housing in the study city has gone through a number of changes in recent years as the province of Ontario devolved responsibility for their social housing stock to local governments and the City Council restructured the organizational environment to reflect these changes. Social housing in the city is now a mixture of city controlled buildings managed by non-profit organizations and rent-geared to income units which may be in either non-profit or privately managed buildings. Low-income individuals wanting to live in social housing must apply to the centralized Social Housing Registry run by the city where they may select which buildings they would like to live in and are placed on a waiting list. Social housing residents who are evicted are not eligible for further social housing.

A second significant change to the management of social housing has been an Ontario court ruling that senior's housing can no longer be restricted to seniors. This policy change has had a dramatic impact on the social housing situation in the study city with instances of crime, victimization, and a declining sense of community being reported in these newly integrated buildings. The case study I initiated in early 2006 was a response to the concerns of seniors living in these building which had become 'age-integrated' and aimed to improve relationships between seniors and younger adults and increase levels of self-governance, community, and in turn safety and well-being amongst tenants. The goal of the project was community building and community-based participatory research was seen as a potential means of achieving this.

On exploring the literature for discussions of age-integration in social housing it immediately became apparent that very little was known about the social effects of age integration or what the ideal generational balance would be. There do not appear to have been any interventions specifically tailored to breaking down age barriers. The literature, however, was clear that age-integration has important implications for feelings of security and victimization. This is evident in research by Newman (1972, as cited in Lawton 1973) who found that both fear of crime and incidences of crime were greater in age-integrated housing projects. Interestingly, Normoyle and Foley (1998) found evidence to the contrary in a US study of 42 housing sites across 15 US cities. These researchers found age-segregated seniors residing in high rises were more fearful of crime than their age-integrated counterparts despite being no more likely to be victims of crime. Only when senior residents were segregated from younger public housing families was the local crime problem deemed to be more serious (Normoyle and Foley, 1998). This literature suggests that the fear of crime amongst seniors may not be higher in age-integrated settings, and that fear of crime may not be related to levels of experienced victimization.

The form that age-integration takes is clearly an important factor in shaping social relations. Heumann (1996) for instance, has studied the effects of mixing frail elderly people and younger persons with chronic mental illness and substance abuse histories and has found that such combinations can severely diminish both the quality of life and the quality of care for the frail seniors, as well as complicate facility management. The author found that seniors spent more time in their apartments due to fear of younger, volatile residents and, as a result, social opportunities were reduced, building safety suffered, external visitors declined and resident stress and turnover increased (Heumann 1996). It is worth remembering, however, that the problems with age-integration found by Heumann are to a high degree due to the fact that younger persons with chronic mental illness and addiction problems were involved. Consequently, Heumann points out that age-integration can be beneficial with the physically or mentally disabled, the terminally ill and for low-income single people without mental health problems (Heumann, 1996:458).

Although age-integration does not automatically result in a higher fear and risk of crime for seniors, the social environment can strongly influence the likelihood of negative, crime-related effects of age-integration. Lawton (1973), for example, found that the fear of crime is especially high where older people live in the same building with teen-aged children of problem families. Furthermore he states that the worst possible conditions for crime are those where there are “vulnerable elderly people, welfare families with problems beyond their ability to cope with” particularly where the housing is situated in an even more troubled neighbourhood (Lawton 1973:173). Lastly, Vélez (2001) confirms that "disadvantaged neighborhood conditions increase dramatically an individual's probability of victimization" (Vélez, 2001:856). In such surroundings, seniors might often be among the most vulnerable victims, since they often lack physical and other means of protecting and defending themselves.

The literature suggests that age-integration can have positive impacts for seniors as levels of cognition, for example, are enhanced through the interactions with younger generations. The community within which one lives, however, is significant in shaping how age-integration affects overall quality of life with those in socially dysfunctional settings, where crime and family problems may be more common, experiencing greater negative impacts from their younger neighbours. Here we see distinct parallels with the discussions of social capital; both bodies of literature suggest that the nature of one's community affects whether social interactions will be beneficial or detrimental to the individual.

Within the context of a small city in Ontario, the collaborating senior's non-profit organization was unique for its emphasis on advocating for its members and promoting activisim – something which most non-profits are reluctant to do because of the potential for their actions to make them ineligible for government funding. The problems seniors living in the city's social housing had experienced in recent years triggered the non-profit to lobby local government; they had supported tenants at hearings and carried out research on social housing issues.

The implementation of CBPR case studies in social housing settings required the support of the housing providers. Two months were spent informing local housing providers of several proposed study and informally discussing the housing situation for seniors in the study city with key figures in the non-profit and government housing arena as a means of relationship building. This process assisted my own knowledge of the social housing options available for seniors and younger residents, the process involved in gaining access to social housing, and the challenges associated with providing social housing. This process, however, was not uniformly positive as many housing providers did not return phone calls or simply did not have the time to talk with me. This appeared to be indicative of social housing organizations, particularly non-profits, where one person may be responsible for managing multiple buildings. The lack of staff resources may be a factor in the reactionary way many housing mangers had been reported as dealing with problems in their buildings.

A steering committee was established in conjunction with the seniors non-profit to provide oversight of the research process, enhance its legitimacy in the eyes of housing providers, and gain the input of those involved in the provision of housing into the study design. The steering committee consisted of individuals representing the seniors non-profit, the city's housing division, the city's social housing management, and my Ph.D. supervisor. The five person steering committee first met in the beginning of May, 2006 to discuss plans for the study and confirm commitments to the steering committee. Out of this discussion three buildings representing different housing organizations were selected for implementing CBPR case studies. The three buildings were chosen based upon varying time lengths over which they had been age-integrated; this was to provide an indication of whether social dynamics change over time.

Having the support of the steering committee to proceed with the study, I began contacting the selected organizations first through the dissemination of a letter outlining the goals of the study and then a follow-up phone call. There are age-integrated (i.e. formerly seniors only) housing organizations in the study city operated by four organizations. Due to concerns that the project not target one particular organization, I needed the cooperation of three of the four organizations. The response that I received from the three originally identified organizations was mixed, which ultimately led me to pursue the support of alternative organizations and the notion of selecting buildings based upon the period of age-integration became untenable.

7.5 COOPERATION FROM THE SOCIAL HOUSING ORGANIZATIONS

The majority of housing organizations required their Boards of Directors to approve the project for it to go ahead; however, it was clear that the housing managers had a great deal of sway with many of these Boards.

Building A

The executive director of the first housing organization approached, managing Building A, proved similarly difficult to pin down and when I finally spoke with her she was quite adamant that the building she managed was senior’s only. This was in conflict with anecdotal reports from residents of the building who claimed that mixed-age tenancy was compromising their living experiences. Another phone call also resulted in no progress and I began to look to other housing organizations.

Months later and still struggling to find three organizations willing to participate in the study, I refocused my efforts on Building A, mailing the proposal with a request that the board review it as soon as possible; a follow-up email with the Executive Director was met with agreement. As the Executive Director was on holiday immediately following the meeting it was approximately six weeks before I found that the proposal had been accidentally left off the meeting agenda. The Executive Director asked me to remind her of the nature of the project, which I did, explaining its goal of involving community members in a collaborative research project. On the spot she gave her approval for me to go ahead with the project by posting flyers/posters in the building. Later I realized that I had, quite inadvertently, failed to mention the study's interest in age-integrated housing settings and suspect that this may have been an element in her agreement.

Building B

The second organization to approve the study is labeled Building B. Building B's agreement, however, followed a drawn out process of contacting the president via telephone and mail. After months of no response, I mailed a copy of the study proposal to both the housing manager and president of the organization and requested the proposal be reviewed by the board of directors at their next meeting. A follow-up phone call with the housing manager was very positive, albeit with the caveat that it would be almost two months before their next meeting due to board members being away over the summer. The study was approved by the board at their next meeting in September, 2006 and was no doubt eased by the number of academics, and particularly social scientists, standing on the organization's board.

Building C

Initial efforts to facilitate the approval of a case study with a third housing organization were met with resistance by the manager due to her high workload. A member of the steering committee who represented the city offered to contact the manager to hasten progress. The steering committee member was able to commit the manager to discussing the project at a meeting of the Board of Directors in August of 2006. At this meeting the board was unable to come to a decision regarding the project as they did not deem their building to be age-integrated due to the only younger adult residents being individuals with disabilities. The organization's board invited myself and the executive director of the senior's non-profit I was working with to attend the following month's board meeting to clear up the age-integration issue and any other concerns surrounding the study. Following the meeting the concern about age-integration appeared to remain and a further written clarification was requested from me regarding the nature of organization's eligible for the study. The senior's non-profit I was working with had experienced difficulties with this organization in the past. The board's tenant representative, in particular, was anecdotally known to be a divisive force in the residence and was negative regarding the idea of the study. Ultimately, the organization declined involvement in the study on the basis that they did not see themselves as a good fit. Following that news, I received an email from a member of Building C's board describing disappointment with the decision and a feeling that the reasons for the decision were poorly articulated but that fear appeared to be a motivating factor. The email is quoted below:

> You have likely had, or shortly will, receive official response to your request to include [Building C's] tenants in your study. I don't really understand why the board decided not to allow you access to our tenants, the reason(s) were not articulated well, fear of the worst possible outcome might best describe it. In any event I wish you luck in your study and wish that our board was more enlightened in their thinking.
>
> (Personal correspondence, board member 15 October, 2006)

Building D

The final housing organization involved in the study had a representative on the steering committee and thus had been involved in the design of the study and took responsibility for ensuring the project was approved by the Board of Directors. Approval for the project was granted in August of 2006 with the criterion that two other organizations likewise agree to participate as there appeared to be a fear that their management practices or tenant relations may be singled out. Once these requirements were finally met in October of 2006 the implementation of the study was further delayed by a review of the data collection instruments and ethics materials by two of Building D's housing managers.

Arising out of the housing manager's review were requests for a number of changes aimed at reducing the possibility of residents portraying the building and the organization in a negative light. Amongst the changes was a request for the removal of a statement on the study information sheet stating: "Any decision to participate (or not participate) will not affect your current or future housing situation." Discussions with former tenants of the organization had indicated prior management practices to be substandard, with harsh measures being applied when problems arose including the victimization of tenants who spoke out about problems within their buildings.[1] Due to both this history of tenant persecution and the ethical responsibility of the researcher to carry out research only when the costs of being involved do not outweigh the benefits these amendments were rejected. The risk to participants of being evicted (however slim) was deemed more significant than any positive experiences which might arise out of the study. The decision was made to pursue discussions with the housing manager via the

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[1] Informal discussions with former tenants of Organization D uncovered experiences in which residents who were deemed to be 'troublemakers' were threatened with eviction if they continued to speak out about the problems within their apartment building. Anecdotally, a number of these senior tenants' health suffered due to the stress associated with their living situation. A superintendent involved in these situations was eventually charged with assault by police.

steering committee meetings; however, difficulties in scheduling the meetings, the late stage of the project schedule, and the changed position of the housing manager stood in the way of this occurring.

7.6 ORGANIZATIONAL RELATIONSHIPS AND PARTICIPATORY RESEARCH

I primarily sought the involvement of outside housing organizations to act as gatekeepers through which individuals interested in the participatory research project may be accessed. Mixed success was achieved in the fostering of relationships with organizations. I identify three primary sources for these difficulties which I discuss in detail below: first, my connection with the advocacy-focused non-profit group; secondly, the contentious nature of the study; and thirdly, the nature of the housing organizations.

Earlier in this chapter, I discussed the nature of the non-profit senior's organization I developed a relationship with as a Research Associate. This organization provided me with office space and a wide range of support from stationary through to Research Assistant staff and reimbursement of some of the costs involved in the study. In return, I participated in a range of organizational activities and carried out a number of volunteer duties. My close working relationship with this organization; however, aligned me with a group who had been active in advocating for seniors caught in difficult housing situations and in many instances, they had come face-to-face with board members or housing managers while supporting these seniors. The executive director and the board members had not hesitated to raise shortcomings in the management of seniors housing within the media and this history potentially contributed to the fear which some housing organizations evidently felt regarding the potential for the study to paint them in a negative light.

Despite the challenges of establishing the case studies, I believe my position as a participatory researcher was facilitated by the nature of the organization’s focus on advocacy. Had I been involved in an organization where advocacy and activism were feared (due to the funding implications) I would not have been as free to pursue the line of participatory inquiry which evolved within the successful case study. It is also unlikely that I would have developed such a close relationship with other types of organizations (such as those that are service-oriented) which enjoy greater opportunities for revenue sourcing, tend to have greater levels of staffing, and less time to devote to building partnerships with volunteers.

A second factor that emerged as significant in influencing housing organization attitudes toward the research project was the overriding goal of addressing age-integration in what was formerly seniors only housing. This issue of age integration was a major stumbling block for a number of the organizations potentially due to the implication that social relations amongst tenants may not be entirely positive and that management might have a role to play in this. There appeared to be an element of protectionism at work with some boards arguing that age-integration was not an issue in those organizations where younger adults were limited to persons with disabilities. In this respect, organizations appeared to be distancing themselves from those housing settings where issues such as crime and verbal abuse had become almost commonplace. In some sense, it also reflects a failure to see persons with disabilities as ‘whole’ people.

The participatory research literature is sparse when it comes to the development of relationships with gatekeeper organizations. White et al. (2004:S5) discuss strategies for developing a positive relationship which includes becoming familiar with the organization, participating in activities unrelated to the project, and showing mutual respect. Once community stakeholders have been identified the researcher must work actively toward developing participatory relationships to ensure that the involvement of these individuals is sustained throughout the research process (White et. al., 2004); issues discussed in more depth within Chapter Eight. While these are good principles by which to work, they are not enough to guarantee success. Perhaps, a more collaborative approach of involving the participants right from the start would have been more successful. Yet the one organization which was involved in the design of the study exhibited distrust and a reluctance to collaborate regardless of their more empowered position.

The final element which appeared to shape the attitudes of the housing organizations was the nature of the boards of directors and staffing. What the organizations shared in common were high staff workloads (particularly amongst the non-profits) with housing managers frequently being difficult to contact and delays occurring because of their workloads. Amongst the three approved CBPR case studies one housing manager bypassed board approval, a second case study was approved at least in part because of the support and presence of a housing manager on the steering committee (despite the problems that later arose), and the third board which approved the study appeared relatively free from the politics which plagued the other organizations. Upon meeting Organization B’s board, I was struck by the relatively low presence of City Council members and the relatively high number of individuals who had strong connections to one of the city’s universities. Through my discussions with board members it became evident that they had an understanding of what I was trying to achieve that the other organizations did not. The board members were also very open in discussing the fact that they had encountered problems with tenants in the past, but their housing units were presently relatively problem free.

The difficulties I encountered getting a participatory research project established with local organizations who appeared threatened by the prospect and reluctant to develop partnerships slowed down the research process and called into question the feasibility of carrying out open-ended research in settings where already marginalized individuals are vulnerable to a large organization – in this instance ones with the power to evict them. Furthermore, the fact that the project was successful only in an organizational setting where academics were a significant presence on the board of directors leads me to wonder whether community-based participatory research in all of its efforts to be grassroots and empowering remains somewhat disconnected from society in the same way as traditional research. Perhaps CBPR is merely a round-about way of justifying the involvement of academics as powerbrokers in what should be a more organic process of community activism? I return to this question in my concluding chapter.

7.7 SUMMARY

While the study city has a rich history of social activism, this richness is paired with a complex social dynamic exacerbated by great economic polarization. The city is small in population size, limiting the number of non-profit organizations servicing those in need and meaning that those who stand out for a particular reason, whether it be because of their HIV status or a disability, are particularly visible. What became apparent in my efforts to establish a participatory research project was the central role that these local organizations play in establishing participatory research projects. The financial and staffing constraints of these organizations as well as local politics can substantially shape the direction of participatory research and ultimately cannot be divorced from the success or failure of participatory research.

Chapter Eight

Community Organizing & the Implementation of Community-Based Participatory Research

Establishing the community-based participatory research (CBPR) case studies proved to be the most difficult aspect of the research process. While the active support of gatekeeper organizations can facilitate the establishment of a project, the likelihood of community members choosing to participate remains difficult to predict and amongst the most poorly understood issues within the participatory research literature. Drawing predominantly from two case studies, one focusing on people living with HIV/AIDS and the other with individuals living in social housing, this chapter aims to provide a better understanding of the factors that influence community decisions to become involved in CBPR.

Caution and cynicism continue to pervade public views of academic research, particularly amongst marginalized groups who have been the subject of much research in the past (Ontario, 1993, as cited in Institute of Health Promotion Research, 1995). Participatory researchers must be very open and explicit about their goals when they are involving community members in research because of this history. The difficulty of attracting community members into a participatory research project is slowly being recognized (e.g., a recent government instigated health promotion project was unsuccessful due to community misconceptions of what the project would involve according to the Institute of Health Promotion Research, 1995). To overcome some of these challenges the researcher must assure potential stakeholders that the research is being instigated with their interests as the focus, and that the concerns of the community supersede their own research goals (Institute of Health Promotion Research, 1995; Ritchie, 1996). This means discussing the extent of the researcher's involvement in the project and their motivations for its instigation.

Living with HIV/AIDS and having a physical disability are very different experiences yet many commonalities emerged between the two groups as both experienced significant social and physical challenges to living with their conditions, both groups raised the issue of discrimination and stigmatization in the broader community as strongly impacting on their lives, and both faced numerous barriers which prevented them from being more involved in community life. This chapter begins with a focus on the challenges of living with HIV/AIDS with a particular focus on stigmatization. I examine why the CBPR project was unsuccessful with people living with HIV/AIDS and compare this case study with the social housing case study to identify reasons for its lack of success.

8.1 EXPERIENCES OF STIGMATIZATION

Stigmatization is conceptualized in this study as an outcome of the negative social processes which facilitate exclusive forms of bonding social capital to the detriment of others in society. This process of differentiation is so common as to be overlooked and even sanctioned by society in quite overt ways, if we look to the publicizing of child sex offenders as an example.[2] Stigmatization is believed to provide communities with a level of protection from a perceived risk that the marginalized group or individual presents to them. Alternatively, the process of stigmatization also serves to strengthen the dominant community as this ‘othering’ reinforces the dominant group’s values, beliefs, or bodies (Gilmore and Somerville, 1994).

The process of stigmatization is referred to by Bourdieu (1992) as symbolic violence (see Chapter Five) and is unique for its location within a broader understanding of society as shaped by an ongoing series of socially and culturally significant actions which position oneself or reinforce one’s position in society. The symbolic violence of stigmatization while intended to protect the interests of the dominant group may in fact achieve the opposite particularly so far as health conditions are concerned as individuals may be reluctant to pursue diagnosis or treatment options for stigmatized conditions for fear of becoming the ‘other.’ In some circumstances the process of stigmatization may lead to the mobilization and thus the strengthening of the subordinate group; this practice is evident in the case of HIV/AIDS mobilization in large cities.

8.2 STIGMATIZATION & HIV/AIDS

The initial spread of AIDS throughout North America was strongly associated with gay men, so much so, that the disease was initially labeled GRID (Gay Related Immune Disease) (Lorber, 1977).[3] The concentration of AIDS amongst gay men created a

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[2] This practice is evident in public lists of sex offenders. The Michigan State Police, for example, have an on-line searchable database allowing the public access to the names, photographs, and addresses of registered sex offenders.

[3] The first signs of HIV/AIDS in the developed world were incidences of an unusual pneumonia in Los Angeles and later 41 cases of a rare cancer in New York and California, all amongst gay men (Atkins, 2003).

landscape of vulnerability within the urban gay enclaves of cities such as New York, San Francisco, and Vancouver where fear and stigma was increasing: “By 1983 it became clear to most [Vancouver] West Enders that there were sick and dying gay men locally and the problem was growing rapidly (Brown, 1997:40).” Social movements began to take shape in these cities in response to misconceptions around the disease, at a time when governments and the media were rendering AIDS as a ‘gay disease.’

Throughout the 1980s, the threat of HIV/AIDS began to have an enormous impact on gay men as friends and partners became infected and many political and religious groups sought to render its spread with a moral brush. At this time public attitudes toward AIDS were fuelled by existing homophobia and the discourse of health professionals and researchers was doing little to address the social impact of the disease. In the public health literature, a rhetoric of risk emerged which distinguished between those who were deemed likely to contract HIV/AIDS (primarily, gay men, drug users, and haemophiliacs) and the rest of the population (Brown 2000). This distinction served further to stigmatize already marginalized groups and foster a false sense of security amongst the population who was not deemed ‘at risk.’ Amongst the first to challenge this moral ethos and advocate for people living with HIV/AIDS was the AIDS Coalition to Unleash Power (ACT UP) which marked the beginning of a grassroots gay political movement which tied the fight for gay rights and gay identity to AIDS activism (Brown 1997; Geltmaker, 1992). Since then the movement has expanded to meet the needs of the non-gay population living with HIV/AIDS.

AIDS activism has not, however, been restricted to those living with HIV/AIDS. Law (2003), for example, examined the quest of residents of West Hollywood to increase government provision of counselling and home based care. Law found that while

HIV/AIDS activism originated amongst gay and bisexual populations this sense of community extended spatially to impact on the non-gay and bisexual population in the local area: “the West Hollywood case shows that under certain conditions strong support can be developed for the provision of services even among people who do not imagine themselves likely to use the service (Law, 2003:20).” The example of West Hollywood illustrates the mainstreaming of citizen activism and the overcoming of stigma through the extension of community involvement beyond traditional issues and locations. This is a concept adopted by Brown (1997:5) who situates AIDS activism at the intersection of ‘political obligation, rights, and inclusion.’ Citizenship has traditionally been conceived as opportunities provided by the state for community involvement but increasingly we are recognizing the importance of political action outside of traditional community structures (Brown 1997). A large body of literature cements the importance of community mobilization for triggering action on AIDS and addressing the needs of those affected during the 1980s (Atkins, 2003). The historic importance of the gay community to AIDS mobilization raises concerns over the political implications of the increasingly diverse population living with HIV/AIDS today.

Achieving community participation is arguably the biggest challenge for a researcher interested in initiating a participatory research project from scratch as the abundance of social capital literature in the past 10 to 15 years has told us that community participation, and altruism in general, is in decline in North America (Putnam 1990). A limitation of this study lies in the lack of historical context we have for HIV/AIDS activism in smaller cities (e.g., the Canadian AIDS Society (1994) notes that throughout the 1980s much of the AIDS movement in Canada was contained within the major cities of Toronto, Montreal and Vancouver). “Such a narrow and precise lens on urban AIDS politics can trick our geographical imaginations into assuming that we need to look only at these three cities to understand local AIDS politics in North America. We may forget that there has been a local politics of AIDS everywhere." (Brown (1997:32). Likewise, the process of stigmatization differs from city to city and is likely closely tied to community activism, a possibility examined further in the following sections.

8.2.1 Introduction to the Participants Living with HIV/AIDS

The six interview participants living with HIV/AIDS represent a demographically disparate group of people with very different life trajectories. I want to take the unusual step of introducing the participants by summarizing the direction of their adult life and providing an interview excerpt that depicts their present outlook and the relative importance of HIV/AIDS to their lives as a means of contextualizing their later discussions of living with HIV/AIDS.

> 'A's' partner was living with AIDS when he passed away. In his 60s he continues to volunteer with an HIV/AIDS agency.
>
> **A:** "I've told them at all the [HIV/AIDS] conferences 'If anyone wants to talk to me I'm here, I'm here as a caregiver, I'm here as a listening... believe that if I can help more, more people like I've helped my hubby, then I'm going to be a better man for it."

> 'B' is a woman who spent time in prison where she was infected with HIV through an ear piercing.
>
> **B:** "I was afraid of dying, I didn't want to die. I did at the beginning, like I said, but as I started to get sober and clean, I didn't want to die so I look after myself now. I eat well and I go to lots of meetings because I need lots of meetings. I go see a counselor... and he's helping me deal with my sexual abuse and my beatings I took as a kid from my stepfather and he's helping me deal with that. But other than that, I don't know, my life is better since I got HIV..."

> 'C' is an older man who has been socially active in the past but is presently dealing with non-HIV related health problems.
>
> **C:** "...it's difficult for a lot of people and I know myself I just don't have enough energy and if I got a job and went off disability and then I wasn't able to work anymore, it's just so hard to get back on the disability [benefit]."

‘D’ is a man who had been a drug dealer and spent much of his adult life going in and out of prison

D: “I mean, I was a young, excitable drug dealer when I was younger, a long time ago. When I was younger playing the role, you know, ‘I’m the tough guy’, and ‘we know what you’re all about’ well I’ve grown, I’ve changed. I’ve got a 22 year old son… I need to be able to grow out of my label”

‘E’ is a woman who was diagnosed with HIV 16 years ago. She describes herself as a housewife, though she works part-time and aside from having trouble gaining weight says that she is healthy.

E: “I have a meeting once a month. Yup, darts every Thursday, I have darts tonight, I do a lot of things, I help the legion out.”

‘F’ is a gay man who is a receiving a disability benefit and is involved in the community as much as he is able.

F: “I was at a workshop a couple of years ago in Montreal that HELCO put on […] and they did a – it was basically coming up with projects to reduce discrimination, and mine was to use art as the medium… .It’s amazing once people get creative they start talking and dialoguing and those barriers and walls that were up are gone. I think art can be a very useful tool…

As indicated by the above quotations the six participants come from very diverse backgrounds which have influenced how HIV has changed their lives. The remainder of this section focuses on how their individual life paths affect their experiences living with HIV/AIDS with a particular focus on stigma.

8.2.2 HIV Diagnosis & Life Changes

The interview participants were asked to reflect on how their lives had changed since being diagnosed with HIV. Many participants reflected back on the people they were immediately after diagnosis as an indicator of how far they had progressed psychologically and behaviorally. Only those participants who discussed being drug users (‘B’ and ‘D’) mentioned the state of their lives prior to diagnosis and the picture they painted was rather bleak being unable to quit using alcohol or drugs, having no permanent home and not looking after their own health.

> **B:** I was so messed up when I found out on drugs. I'm nothing what I used to be like, I have my own place now you know, and I've never had that. You know I've had them but I always took off because I was too high to pay rent or whatever. But I mean, I get up in the morning, I eat, I take my medication, and I usually sit around and do nothing, mostly. Then I take my medication in the afternoon at one. And then I take them at night time. And um my life hasn't really, its got better, to be honest with you. HIV has changed my life for the better.
>
> **D:** This disease made me grow up, this disease helped me respect myself. Of course I hate it it's devastating to my life – but it made me look after my diet, it made me pay my rent, it made me quit drugs, it made me quit going to jail and I couldn't cope doing any of those things.

Wilton (1996) developed a framework for understanding the stages through which an individual progresses following diagnosis with HIV. The stages include shock, cocoon, emergence, relapse and recovery and are indicative of a cyclical process. Wilton (1996) suggests the initial 'cocoon' stage may be a phase, lasting varying lengths of time, in which people renegotiate their personal space. This early period following diagnosis was described by a number of interview participants as being quite isolating and often involved destructive behaviours. Subsequent phases of social disengagement, as described by Wilton (1996), are strongly connected to one's health status. These stages were evident in the discussions with stakeholders regarding their experiences of HIV/AIDS but appeared most pronounced amongst the participating former drug users. The study did not, however, include anyone who described themselves as an active drug user and their experiences of HIV/AIDS is likely to be quite different.

> **B:** Because I was seventeen years old and I found out I was diagnosed with HIV, and I wouldn't want another seventeen year old going through that same thing - at all. I tried to commit suicide when I found out, I was pregnant, I was seven months pregnant...

> **A:** He didn't want, he didn't want, at first, he didn't want to be around anybody. So he were like a recluse for a while. And finally I said, I said 'Bobby this has got to stop, you've got to get out.' And so I forced him to get out and start going around visiting our family, visiting our friends. And finally so, the next thing I know he's gone out to the mall, he's walking around the mall, he's shopping, and he just got it in his mind then that 'it's not the people, it's me,' he said 'it's not all the people, it's me doing all the suffering because I'm blocking out everything completely and just being a recluse'... .His attitude in life about having HIV – at first it was 'I just want to die.' But after, once he got his pills reduced down he said 'oh' he said 'what's this, I've been here 7-8 years with HIV, I'm going to start living life the way it should be and not worry about nobody but himself.'

That Wilton's (1996) work continues to have relevance is insightful given the advances in antiretroviral medications and HIV affecting a broader cross-section of the society than his, primarily gay, male study population. The interviews carried out for the purposes of the current study suggest the earlier stages of Wilton's (1996) framework are still valid with participants experiencing shock at diagnosis and going through a significant phase of social withdrawal this finding suggests earlier stages are still connected to fear of dying and stigma. Later phases of relapse and recovery within Wilton's (1996) framework were not described as acutely by interviewees though many participants made clear that at times their health restricted their social activities. The interviews indicated that consistent with this stage of emergence was a new awareness of the importance of one's health to survival which prompted a number of the study participants becoming vigilant in ensuring they were doing all they could to keep in good health, seeing this as a tool for extending their lives.

> **D:** I was afraid I was going to die. Quickly too, I was really quite frightened, I had a T-cell count of 200 and yours is about 9-1200. The doctor's helped me to understand that, far from me to assume anything about yours, but a normal count, a person in health is 9-1200 and by T-cell count was 2 [hundred]. They don't give you a life expectancy down there, they just say 'well, we'll wait and see.' And there is a 'well everyone just goes and dies' attitude too. I mean, these floors, these AIDS/HIV floors, there is a time to die idea floating around there and I don't wish to buy into that idea
>
> **Sarah:** So you're much more focused on taking care of yourself now.

> **D:** That's all I wish to do, it's become an obsession with me – that's not an unhealthy obsession. I have a steady regimen of looking after myself, I go to bed at the right time, I eat the right foods, vigilantly, I take water, there's so much to do with your body. It's a full-time job.

> **F:** ...I've been lucky, my health has been fairly good, I've stuck to the pill regime and it seems to have worked for me. But I see it being an area.
>
> **Sarah:** Are you on a lot of pills?
>
> **F:** I just stopped two months ago so I'm not on any meds, but I was on the same cocktail since '97 so I think sticking to that one cocktail worked but my body became just toxic. My liver was nuts, my blood pressure and cholesterol high [laughs] some really bad things, so I'm on a break for a while.

Antiretroviral medications were a complicated issue for many and were taken by most participants. The quotation (above) from 'F' indicates the problems that can arise from taking these medications for many years while others had difficulty finding a combination of pills that did not have severe side effects. Another participant ('D') was no longer taking medication because the hospital clinic had ceased to see him as a patient due to their perceptions that he was a behavioural risk.

8.2.3 Participant Experiences of Stigmatization & Living with HIV/AIDS

The interview participants were asked about the implications of being HIV positive in their interactions with the wider community. Stigma was an issue that repeatedly arose throughout the interviews impacting on their lives most commonly in response to the wider community's understanding of HIV. Many of the interviewees explained that they were often slow to tell people that they were living with HIV because they were scared about the kind of responses they would get.

> **A:** He would never tell anybody, certain people, that he had HIV for the longest time because he was scared he would lose them. And that's what a lot of people have had happen, they've told people, good friends of theirs that 'I have

> HIV' and they didn't want any more to do with them, anything more to do with those people, and that's the worst thing, the hardest thing to have happen.

> **B:** Oh yeah, I tell them I always. I used to be really, really ashamed of it, at first I didn't tell anybody. Unless I wanted to get dope, and then they'd feel sorry for me! But today I let anybody I know that I'm in contact with that I have HIV in case something happens.... No, well, in 2000 when I was really ashamed of it when I went to treatment I was ashamed to share it because I thought no one would like me because I had HIV. But the people were really nice to me, they didn't judge me – except one girl, of course, she spit in my face and said 'I hope you die of AIDS.' But that's the only really bad thing that's happened to me. I've never really been judged by people with [having] the HIV. But some people are still really ignorant about it.

These quotes provide examples of the common issues interviewees experience in dealing with HIV and particularly the stressful process of explaining your HIV status at the risk of facing discrimination. The two women I interviewed stressed the importance of telling people around them about their HIV status because of the potential health risks for others if they were to get injured (e.g., in a car accident). This attitude was, however, in the minority and the remainder of the participants were less open about their HIV status. The reasons for being closed about one's HIV status was predominantly assigned to the ignorance of wider community members.

> **B:** I think it's just the disease itself, you know HIV, you know and before I got it I was pretty ignorant about the disease as well, I said 'this just proves that niggers fuck monkeys' I used to talk real dirty about it. And then when I got it my attitude just changed. I got it in jail, through a piercing. I wasn't using needles back then, I was just smoking dope, drinking and I wasn't having sex. So I know I didn't catch it that way, so I caught it from this girl __ __, I can say her name now she's dead pierced my nose with her earring, she took it right out of her ear and pierced my nose with it. And that's how I caught it, in 1995 in jail. And that's how I caught it, and I didn't want to live.

> **Sarah:** What do you think about the awareness of the community?
>
> **E:** It's not, hardly any, 'cos people think that HIV is AIDS and it's not, they are two different things HIV causes AIDS. And when you tell someone you're HIV positive they go 'ew' and they run away from you. It's just, it's not right, it's discrimination. It's not your fault you have it – sometimes it is.

The quote from ‘E’ (above) speaks to divisions amongst people living with HIV. When ‘E’ spoke about being infected, she talked of being a teenager who felt that nothing bad would happen to her: “I said that, I’m not a bad person, why am I sick? Somebody just happened to be an asshole and give me the virus.” ‘E’ implies that some people are victims while others, perhaps drug users, are not. These divisions arose a few times in the interviews and it became clear that some people were experiencing discrimination as a result of their identity as well as their illness. Termed ‘layered stigma’ this may be particularly damaging because not only does it reproduce outside societal stigma within an already stigmatized population but it decreases the likelihood of the broader affected group mobilizing in opposition to the stigma.

The diverse ways in which stigma impacted the interviewees speaks to their disparate backgrounds. For the gay men interviewed, issues around sexuality appeared to have been long-since resolved whereas HIV continued to be socially problematic. As former drug users, B and D still faced the stigma of being seen as users. B, for example, relayed to me the experience of being suspected by her AA sponsor that she was looking for drugs on the days that she missed an AA group when she was actually in too much pain to attend.

> **D:** I also must admit that I’m a recovered drug addict. So you’ve got an IV drug addict whose got HIV and they think that’s a loose cannon in their eyes, spreading the disease in their eyes, and possibly there’s a fear in their eyes. A subliminal fear that they get – oh, he’s going to bring AIDS to our community. That’s a label that I grab unfortunately, so users, people who don’t use drugs don’t get that level. Unfortunately that’s something that I found out when I stopped my drug use, it took me ten years to calm it down.

The stigma experienced by ‘D’ was most extreme as he felt he had been labeled by the wider community both for his HIV status, his former drug using/drug dealing status and past violent/criminal behaviour. Stigmatization may be more extreme in smaller cities where one’s reputation is communicated faster and is more difficult to escape even once one’s behaviours have changed.

8.3 INTRODUCTION TO THE SOCIAL HOUSING PROJECT STAKEHOLDERS

The stakeholders in the social housing project were primarily seniors roughly half with physical disabilities requiring wheelchairs; the remaining stakeholders were able bodied. Below, I briefly describe the stakeholders’ roles in the study, their relationship to the social housing ‘community’ and the nature and extent of their involvement in the CBPR project. This overview is intended to provide an understanding of stakeholder turnover in the project and its evolving nature. In some instances, the lines were blurred between the active participants and those inactive as meetings would often take place in locations where other residents were already socializing leading them to either join in with the project meeting or sit in but not voice their opinions.

> R’ was the first stakeholder I was in contact with; she had a leg amputated due to diabetes complications and relies on a wheelchair for mobility. ‘R’ was instrumental in bringing others into the project and encouraging people to attend meetings. ‘R’ continues to be involved in the project.

> ‘S’ was involved in the project from its inception. As the project advanced she was in hospital for a number of weeks for operations and recovery. A wheelchair user with health needs requiring support, meeting times, often clashed with a caregiver’s arrival and gradually she attended meetings less regularly even when she did have the opportunity; however, she continued to request printed material related to the project.

> 'T' is a woman involved in the early project meetings but ceased involvement in February of 2007. She was active in church and family commitments on the opposite side of the city but had few ties to the local community.
>
> 'U' is the only male who was a member of the group. Also a wheelchair user 'U' has diabetes. He was actively involved in the project at the beginning; however, after a falling-out with another group member his attendance became sporadic. He did, however, remain positive about the project during phone conversations.
>
> 'V' is one of the older members of the group. Her attendance was also sporadic and largely peripheral to the project.
>
> 'W', and 'X', like 'T', are able bodied women and were involved at the beginning of the project but ceased attending meetings in the early part of winter.
>
> 'Y' became involved in the project two months after its inception. A friend of 'R', 'Y' resides at a nearby apartment building. A wheelchair user and involved in local disability issues, she continues to be actively involved in the group.
>
> 'Z' was the last member of the group to join and, while an acquaintance of 'Z' contacted the group through the parallel transit service participant recruitment effort. A disability advocate and with a strong interest in increasing accessibility, 'Z' was the most experienced advocate and continues to be involved.

The nine group members were overwhelmingly female, were aged between 40 and 80 and lived in age-integrated social housing buildings. Four of the stakeholders were users of wheelchairs and many others talked of the possibility of their health declining and needing to use the parallel transit service.[4] Most significant, however, was the turnover amongst stakeholders with only two of the original group members continuing their involvement to the project's completion.

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[4] The parallel transit service is the study city's primarily publicly funded transportation system for persons with disabilities.

8.3.1 Living with a Disability & Life Challenges

Most of the disabled stakeholders involved in the CBPR project faced chronic, multiple health conditions which impacted on their everyday lives in very significant ways, through the need for frequent doctors visits, hospitalizations, isolation, and the compromising of one's ability to care for oneself and one's homespace. Indirectly, these health conditions contributed to loneliness, frustration, and impacted on one's sense of self, as illustrated in the quote below where 'Y' discusses her frustration at being unable to take care of her home:

> **Y:** I know it's hard for me in here because my house used to be spotless, just spotless.... I don't know how many times [my son has] been to my place and said oh mom, I'm never going to keep my place like this. But, if I could do it then... so it's, it's bad, like there are so many issues.

The research stakeholders living with disabilities faced multiple, immediate challenges to their day-to-day quality of life. Many of these challenges were identified as being exacerbated by the limited or non-existent home-care support provided by the province. The stakeholders discussed the impact that service cut-backs had on their housework, the regularity with which they were able to shower following an operation, the increased reliance they had on family members to support them, and the implications for those without family members who could assist them. The stakeholders were frustrated in instances where they were forced to ask family members to carry out caregiving activities particularly those of a personal nature which had previously been private.

> **R:** I used to have to take my son, poor little [son], I used to have to take him in the bathroom with me and he used to have to help me down on to the toilet and back up after I was done and I felt bad for doing it but there wasn't anything else I could do... if they had a stationary commode over the top of the toilet with the arms on it that you can hang onto and sit down and it would be up high enough that you wouldn't be trying to get right down on the toilet seat. People just don't understand about handicapped stuff and at the [hospital], the orthopaedic clinic

> they have a handicapped bathroom - it's got one bar in it and that's it so I can't use it either because I can't...there's nothing for me to hang on to to get down onto the toilet.

As the quote from 'R' above illustrates the stakeholders were frustrated with what they saw to be a tremendous amount of both public and organizational ignorance toward the needs of persons with disabilities. The poor provisions for impairments within health care facilities was a major focus for the discussion and is particularly disturbing given how heavily these facilities are used by persons with disabilities. It was clear from discussions with stakeholders that there was much more that needed to be done to enlighten the public and increase inclusion of people with disabilities into mainstream society.

8.3.2 Stigmatization of Stakeholders Living with Disabilities

The issue of stigmatization was raised in the final interviews by two of the four research stakeholders with physical disabilities. The lack of prominence they gave to this issue however, I believe, belies the importance of stigmatization to the stakeholder's lives given the frequent discussions of discrimination and negative public attitudes which took place during the project meetings. Often, it appeared not to be the presence of a wheelchair in and of itself that was the source of stigmatization but bodily difference through a mastectomy or the amputation of a leg, as discussed in the quote below:

> **R:** That seems to throw people off; they don't know how to react around me now that I don't have my leg.
>
> **Sarah:** Really?
>
> **R:** Yeah.
>
> **Sarah:** People that you've known for a while?
>
> **R:** Oh yeah. People that I've known for years and it's funny because I...this girl phoned me about a week ago...I haven't heard from her in probably five

> years, a few years and she was talking to somebody that told her I'd lost my leg and right away she got my phone number and phoned me. She hasn't bothered with me in years, like I said and just said "Oh my god, you've lost your leg!" And I said yeah, over a year ago. It kind of amuses me because of how people act when they find out that I've lost my leg, even two of my sisters that I haven't talked to in years.... Oh, they both phoned me and said, "Oh my god, I've just heard that you've lost your leg!" I said to my son... it doesn't take them long to come out of the woodwork.
>
> **Sarah:** So do they stay in contact, or do they just want to phone and say, "Hey, you've lost your leg."
>
> **R:** I haven't heard from them since.

Most often raised throughout the project meeting focus groups and the final interviews were experiences of discrimination directed from both the wider community and health and disability workers. In discussions, the stakeholders attributed the source of this stigma, in part, to the prevalent discourse of equality and public resistance to the amount of time and money being invested into allowing people with physical disabilities equal opportunities in society. The stakeholders felt the equity movement, while clearly necessary and needed, was used by some individuals to argue against helping persons with disabilities on the basis that they want to be treated like everyone else.

> **R:** Well I've found, since I had my leg off, that some places that you go people just...they can't be bothered with you - they won't get out of your way, they won't do anything to make things easier for you and that other people can't do enough for you.

> **Z:** There's a lot of workers I get that are quite judgmental and I find more negative than they need to be and I find there's very much this sense, especially, I hate to say it, amongst the younger generation about entitlement; it's your right and you've got people who are being quite vocal about that and I think we've got to return to our encouragement of okay this is the way it is, let's make the best of this situation and let's build on it. Yeah, maybe it sucks, but we can find what the strengths are and build up on that and that would lick a lot of the problems in society.

From the interviews and focus group discussions it was evident that persons with disabilities were often the target of layered stigma from the public when their bodies did not fit the ‘norm.’ Differing from people living with HIV/AIDS, however, was the fact that this layered stigma was not widely internalized within the ‘community’ to form divisions.[5] The stakeholders who participated in the parallel transit service study had a range of health problems which had led to their use of a wheelchair but none of these factors, nor demographic factors, appeared to work against community mobilization. Perhaps most importantly the broader community of social housing residents was supportive of those with disabilities and recognized the difficulties that they faced and the need for change by proposing and supporting a study focused on the parallel transit service. Discrimination and stigmatization were felt by the disabled stakeholders; however, their supportive community may have had a buffering effect on their own lives and contributed to the successful establishment of the CBPR case study.

8.4 THE SOCIAL CAPITAL CONNECTION

The two settings within which the case studies were to be implemented differed significantly in their construction and experiences of ‘community.’ The importance of social capital to the establishment of a CBPR case study is presently poorly understood likely due to the rarity of the researcher being involved in the community organizing aspects of the project as happened in this context. Further, the social capital literature is silent regarding how social capital is fostered within communities and how we may draw on it to mobilize community members. The following sections involve a discussion of the nature of social capital and social cohesion in the two case studies. I conclude by

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[5] The exception was in comments from ‘Z’ regarding divisions between blind persons and people with other physical disabilities.

hypothesizing as to what effect this likely had on the success in establishing the CBPR case studies.

8.4.1 Community Involvement - People Living with HIV/AIDS

> **Sarah:** Are there any community projects you're involved with, outside of [the agency]?
>
> **E:** Oh, I play darts, I'm in the Ladies Auxiliary, I play Euchre, Crib, I'm a housewife, you know, I'm an aunt over and over. I have a good life, I'm doing really great, my counsellor is really great. I quit drinking, it's going to be 6 years the 31st of December. No alcohol, I quit smoking, it'll be 4 months on the 22nd...

> **D:** Yes, my neighbourhood took me in, my co-op supports my illness very much and I've only seen that happen in the last three years. All of my managers and my landlords for my building we all look out for each other in a human way, it has nothing to do with HIV but they have told me specifically 'we don't tolerate discrimination or racism in these neighbourhoods.'

The social networks discussed by interviewees are an important indicator of the resources available to them in times of need and their sense of connection to the local community. While the interviewees discussed a wide variety of social networks including connections to the local HIV/AIDS social service agency, those participants actively involved in HIV/AIDS issues did not appear to be united in pursuit of a given cause and did not discuss the presence of an HIV/AIDS 'community.'

> **Sarah:** So, have you been involved in any activities specifically related to HIV?
>
> **C:** Yes, well it was about 8 years ago now, I was on the board of directors at ____ for a short time. And uh, always any kind of volunteer work I can get involved in, volunteering. Actually I'm not too involved at the moment, I've got one meeting that I come to here about every two months but I just had a serious heart attack.

Four of the interviewees living with HIV/AIDS described very high levels of community involvement and for the male participants a large component of this involvement appeared to revolve around connections with the HIV/AIDS social service agency in a volunteer capacity. An important role for the paid staff was as volunteer recruiters and social facilitators fostering a sense of community within the agency which ultimately revolved around their presence – duties which were consistent with the goal of providing social support.

> **Sarah:** How about you tell me what you're currently involved in so far as community activities go?
>
> **D:** Um, I'm currently involved in, I am, I keep an ongoing rapport with [the agency], I am a part-time writer for [the agency's], for the, newsletter, that's how I'm currently involved at the moment.... Um, I am a cleaner, a volunteer cleaner at the co-op where I live, I do the cleaning there. I'm about to be hired for a part-time community job doing that.

For participants 'B' and 'C', their social involvement had been held back by their health conditions causing a large part of their days to be spent at home. For 'B', her current apartment was her first sense of 'home' in many years. For 'C', the need to take medications every few hours severely restricted what he sets out to do in the day. He aimed to get home in time to take his medications due to the stigma of taking pills in public; concerns which had also been experienced by 'A's partner:

> **A:** Well, as the years went by, from 95 until I'd say about 98, he really didn't see too much. But once he started getting out and around a bit more, like coming up here and volunteering, and doing things, and going out and visiting with people who had HIV, he found out that people were becoming more aware of it. Like he said, even two weeks before he died, he said 'you know,' he said 'people are still ignorant on a lot of things'

Stigma was articulated by participants as a significant source of discomfort when becoming involved in community activities. The city in which the study took place is small in size and often described as insular in nature which had repercussions for participants. 'D' talked about the discrimination he has faced as a drug user in the broader context of a conversation about acceptance within the community. Having lived in the city since he was a youth, he felt it was difficult to escape from stereotyping once he had already been classified as a social ‘problem.’

> **D:** I have a- isolation situation where I find that community does not wish me to be in their community, straight up. And I, I’m not down on them for anything, I love everybody, and I find community involvement impossible. I was really harmed and, physically and mentally – not with their intention, the public’s intention, I don’t wish to get it wrong here, but I was seriously harmed when I tried to participate with anything that’s with the public. I was told they didn’t want HIV positive people around them. And I suffered a few nervous break-downs after that, a few years back there.

‘F’ talks about the stigma that exists between different groups living with HIV.

> **Sarah:** So do you think [the diverse user backgrounds] affects the quality of the service at all, or just the ability to get people involved?
>
> **F:** It’s um, a challenge, most definitely, to get people together, and even to get them to walk in the door of [the social service centre]. I notice the gay men have really dwindled, they don’t come here anymore, they say it’s all druggies – whatever, it’s an illness. So there shouldn’t be the division lines but there are. And I mean when there are a lot of gay people here the heterosexuals all say there are too many gay people. So I mean those are barriers that have to be brought down…

‘F’, who is on the board of the social service agency and an HIV/AIDS activist, draws attention to the challenges which have arisen as the demographics of those diagnosed with HIV have changed. Adding to perceptions of changing dynamics amongst users of the agency was the establishment of a methadone clinic across the road from the social service agency leading many people from the methadone clinic to use the social service agency.

The barriers that interviewees cited to community participation varied, from the cost involved in attending events through to lethargy. Although a number of the interviewees were involved with the social service agency, including volunteering on a regular basis, none brought up the need for any kind of support group based around the service. Furthermore, there seemed to be divisions as to how the interviewees participated with only the gay men being involved with the politics and running of the agency, two having served on the board, and one referring to regular attendance at provincial conferences despite the associated challenges. It was also evident that the community involvement was fostering individual rather than group empowerment as volunteer activities administered by the HIV/AIDS organization were tailored to the individual needs and group activities, such as craft days, had low turnout. There is, however, little doubt that the simple act of being present at the organization through any form of volunteering enhances one's connections to it, and assists in the fostering of a sense of community.

8.4.2 Community Involvement - the Social Housing Case Study

The stakeholders taking part in the final interviews within the social housing case study were all individuals with disabilities and this had impacts on their levels of community involvement. The social housing setting was located near the outskirts of the study city poorly served by the parallel transit service. One stakeholder, 'R', expressed continued frustration over the course of the project with living so far from the centre of town and hoped to move to another apartment building where two other stakeholders resided which was much closer to town. From there, she reasoned, she would be able to use her mobility scooter to get around town as the other stakeholders did. Incidentally, those stakeholders were also much more involved in community activities and organizations.

> **R:** Ah, there is no place that I know of right around here [for seniors to socialize]. I know they, they ah- play Euchre over at the church once a week, but other than that, I don't think there's anything that goes on out here. And I think, I think that, I think that would be good because you can't sit in an apartment day in

> and day out and not have it have some effect on you. So, I think that would be good. Something for seniors to do. And, ah, I don't know whether there would be any use of saying, it would be nice if the [parallel transit service] was a little more dependable and you could go places. But, you just... if you have to plan two weeks ahead of time- [laughs]. We've even talked here, but, they won't even consider getting a bus for this place. And it would, you know, it would be nice if, if they had a small bus that they could take us out to shopping somewhere or, you know.

Stakeholders 'Y' and 'Z' were both actively involved with disability issues in the study city. 'Y's involvement was focused on the local rehabilitation hospital where she volunteered and was a strong advocate on the patient council. 'Z' had been involved in access issues at the city council level and was deeply involved as a personal advocate on behalf of many of her friends and acquaintances. Both stakeholders were acutely aware that they enjoyed somewhat privileged positions in comparison to others with disabilities simply because their health status allowed them to be involved and they were strong enough voices to also speak for others, though this was often a frustrating position for 'Y' who wished more people with disabilities would speak up.

> **Y:** If you don't get enough people out to speak up and- because let's face it, everybody looks at me at [the hospital] now and the main reason they'll say yeah ['Y'], numbers, numbers. Well, if you know, do something to get people out because you're not going to get anywhere unless you do. And some people, yeah they'll sit and they'll say well this should be done and that should be done but then when you get the chance to do it they turn their back and walk away so I mean what do you do? It's just it's crazy...absolutely crazy and as 'Z' said there the other night too, like she doesn't just do this for her, it's for others that she knows that are handicapped or for those that might be handicapped even if you don't know them. But like it's bad enough now, but if they don't do anything to change the system that is crazy, if they don't do anything to change that well then there's never going to be any changes and nothing's ever going to get any better for them, no matter who is coming out handicapped, or whatever their disability may be, it's...I don't know...I really don't. I just get so...

Geography played a significant role in shaping community involvement in the original social housing site due to its isolated nature and few of the residents having private transportation. This isolation made the social nature of the housing setting all the more important for the residents. During the project meetings and the final interviews stakeholders repeatedly raised the issue of social cohesion within the building.[6] The stakeholders discussed at length the trend toward older residents remaining in their apartments and refusing to socialize the younger residents. The result was that the same individuals continued to attend all of the social functions and were the ones to get involved in the study.

> **Sarah:** It's funny because, whenever, in the summertime at least when I come over here, there's the same group of you sitting outside and being sociable, whereas the other people I just don't see. It's only the same people that I see all the time. Why is that?
>
> **R:** The rest of them, they just don't come out of their apartments... I couldn't believe it when I first moved in here they had one little bunch that played Bingo and nobody else come in and they did have two women that came in, I guess one used to live here, and they won you'd swear it was hundreds of dollars they were winning and maybe the pots would be $2 or $3 that you'd win and they would get so mad.

Those who got involved in the study also participated in other activities within their building and distinguished themselves from those who were less visible. The social divisions between the more reclusive residents and those who took part in the study are discussed in greater depth in Chapter Nine where it is made clear that the social relationships had an impact on the project outcome. Further influencing social capital in the study building was the nature of the wider community. Set in a low income part of town, some of the residents had family nearby but overall the young age of their external neighbours and the frequent neighbourhood problems produced a disconnect between building residents and their local environment:

> **R:** “It’s an awful neighbourhood [laughs]- I can’t, I - it still doesn’t - how they would, why one would even bother building a senior’s home next to units at

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[6] While this discussion was focused on the study building the stakeholders from another social housing organization expressed similar opinions.

> the.... Since I moved in here, they've set the trees on fire, they set the garbage on fire all the time when it's put out across the road. You wake up at two and three o'clock in the morning to the fire engines and everything, and the – ah -the first winter I was here, the kids all got paint ball guns for Christmas... and they shot paint balls on our windows. And now, this summer, it was Beebe guns [laughs] – I don't – once it starts getting dark I. I close my blinds and I don't open them up again, it doesn't bother what goes on outside I don't open them."

The grounding of the CBPR project in a spatially determined 'community', in this instance a social housing building, had clear benefits for the project as many strong social relationships were already established amongst those residents who became involved in the study. The very fact that non-disabled residents were identifying the need for a project on the parallel transit service indicated the presence of social cohesion amongst some of the building's residents as they were aware of each other's problems and actively looking out for each other. This social cohesion was not, however, all-encompassing as many residents elected not to socialize with others. Furthermore, the building was, in many senses, an island from the local community with residents rarely walking around the local neighbourhood after dark and expressing frustration at the activities of youth which made them feel unsafe.

8.5 ESTABLISHING AN OPPOSITIONAL CONSCIOUSNESS

An oppositional consciousness is the concept of a common issue of concern uniting a group of citizens and triggering community mobilization. The concept is put forth by Robinson (1992) who sees the notion of injustice to be critical to the formation of an oppositional identity. The experiences of opposition within the two case studies were dramatically different because there was such a clearly identified problem amongst the social housing residents and this problem was articulated as a group and fostered through networks of social capital – something absent from the HIV/AIDS case study. There has yet to be an examination of the relationship between an oppositional consciousness and social capital. If we refer back to the discussions of social capital in Chapters Four and Five we can conceptualize social capital as built on the reciprocal relationships between residents. These reciprocal lines of communication and cooperation may also be a necessary component in forging an oppositional consciousness suggesting that everyday social relationships facilitate the emergence of an oppositional consciousness which, in turn, prompts the investment of social capital. Without these connections and resources to draw upon individuals are likely to be isolated and inactive in response to the issues they face.

8.5.1 An Oppositional Consciousness - People Living with HIV/AIDS

The major goal of the interviews with people living with HIV/AIDS was to identify a theme for a participatory research project. Perhaps the most significant common issue shared by interviewees was the effect of stigma on their lives yet only one person suggested a project based on this theme. Other issues raised included the need for a project focused on prevention (raised by two people), the use of art as a medium for personal empowerment (again raised by two people), and addressing the budget limitations of Ontario Disability Support Program (ODSP) (raised by one person). I asked all individuals living with HIV/AIDS how their finances were and all but one felt strongly that they did not receive enough money on ODSP yet, interestingly, only one raised it as an issue that should be addressed by a community project.

> **Sarah:** So what do you think we need to do about this stigma problem?
>
> **D:** I think that more people that are HIV positive need to stand up together and say ‘I wish to work here, I wish to live here.’ I don’t know any, I don’t know any. Like these are all my friends and I know folks that are sick but I don’t know one person who is HIV positive who’ll step outside that and work anywhere.... I think they need to come together and I think that they need to back each other up when it comes to stigma or discrimination. Because it’s such a private problem – and that’s what hurts you so bad.

The interviewees did not identify a strong need for a participatory project focused on a particular HIV-related issue; a lack of consensus and the absence of ideas on the part of some participants threw into doubt the possibility that an ‘oppositional consciousness’ might emerge amongst the community living with, and affected by, HIV/AIDS. After completing the six interviews a renewed effort to get people involved in the participatory project was initiated through mail-out flyers at the social service agency. When nobody got in touch, the participatory research initiative was abandoned as the hoped-for minimum eight participants were not forthcoming and gaining ongoing participation seemed unlikely. A number of the interviewees had got excited about the prospect of initiating a project on an issue that they felt strongly about. But standing in the way was a lack of congruence in ideas across the participants, only half of whom raised ideas which could be translated into a community project. Some participants dismissed their ability to make an impact by suggesting fundraising as a need, or, in the case of B suggesting they ‘did not know about these things.’

> **A:** The only way, the only thing I think I could say, even remotely that would be of benefit for people with HIV/AIDS would be if people would donate more to the HIV/AIDS would be great. Not just to go to the HIV/AIDS funds, but places like the service depots here and the ones in Ottawa, the ones in Toronto, wherever they are there’s an office for HIV/AIDS people...

No sense of oppositional consciousness was forthcoming amongst the people living with HIV/AIDS who were interviewed and so the CBPR initiative was abandoned.

8.5.2 An Oppositional Consciousness – People with Disabilities

The experiences of the research stakeholders in the social housing case study were unified in opposition to the local parallel transit service. At the earliest possible stage of the project, the residents voiced their distress and dismay with the poor services being provided and the negative impacts on their quality of life.

> **R:** And then missed both of my appointments at [the rehabilitation hospital] this week, because I've got my leg and I'm learning to walk again. And, I missed both of them because I couldn't get a bus. And then, I have two appointments next week that I'm going to have to cancel because they're both early in the morning, one is at 8:30 and one is at 8 o'clock and they can't give me a bus because they're doing their school rounds. ... They've got, they've got, as far as I know, they've got 18 buses, it might be more than that. I mean, they could take a couple of buses and keep them for their regular passengers...

> **X:** Now mind you, I don't take them that much because I get so frustrated because like well, when [partner] around naturally he takes me, so there's not a lot of occasions that I need to take the bus. But then when I do need to take them and I'm in a pinch, well you should have phoned two weeks ago. You don't stand a chance of getting a bus now or trying to get a bus to the mass on Sunday morning is just about impossible...

A large part of the success of the CBPR project in the housing setting appeared to be due to the importance of the parallel transit service to the local residents.[7] It was this issue that mobilized the community and continues to prompt action amongst many of the stakeholders. Where things become inconsistent is with regards to the remaining stakeholders who opted not to be centrally involved in the CBPR project, indeed, many residents ceased their involvement completely. The reasons for this appear to be diverse but at the heart of it is the fact that those individuals who dropped out were either not parallel transit service users or were less concerned with the quality of the service being provided.

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[7] In this city, a user of the parallel transit service must first establish his or her eligibility through a medical assessment process. Once eligibility has been established, users are advised to book their trips two weeks in advance to ensure availability of a bus.

8.6 SUMMARY

The recent growth in research drawing on grassroots community mobilization has yet to yield a theory of substance regarding participation (Campbell and Mzaidume, 2001). Past participatory research initiatives have overwhelmingly drawn on existing organizations to collaborate in pursuit of research interests. This approach has the potential to either perpetuate power struggles or successfully build on existing social capital resources within a community. The HIV/AIDS case study was undertaken in a setting where existing social connections were limited and I therefore sought to foster new forms of social capital (Cambell and Mzaidume, 2001). The lack of existing social connectivity was, however, likely detrimental to the formation of a participatory research project as community action is believed to be best facilitated in settings where egalitarian social networks exist without powerful political figures or peripheral members (Feinberget al., 2005). During attempts to mobilize the HIV/AIDS community, I relied heavily on the social workers as a means of connecting with participants, thus adding a disempowering component of to the initiative. Furthermore, network connections which come about through the mediation of a third person are believed not to produce the same amount of community readiness as direct social connections (Feinberg et al., 2005:298).

The participants in the HIV/AIDS case study had extremely diverse backgrounds but shared common experiences in living with the impact of HIV. The interviews provided some evidence that HIV related discrimination went beyond fear of disease to become contingent on personal identities. The social housing case study differed dramatically as a strong sense of social cohesion and inclusiveness was evident amongst the residents participating in the study and stigmatization, while present, was ‘out there’ rather than within the community. The presence of social cohesion appeared to have an important role on the successful establishment of the CBPR project as it facilitated tight networks through which social capital was able to flow. That a large segment of social housing residents were not active in the study or in other building activities indicates the restricted extent of this social capital.

I was working towards public participation in research but participation in the pure sense of ideas originating with the community. The voices of people living with HIV/AIDS are muted by the attitudes of society an issue less prevalent amongst people with disabilities, and this is simultaneously a reason why participatory research may have been of value in this context, and why I had difficulties in gaining participation among those with HIV/AIDS. The outcomes led me to question to what extent ‘pure’ participation in research is possible – have we disenfranchised the public from the research process to a level where participation is just not a viable possibility? And, simultaneously, how forceful and persistent should a researcher be in pursuit of participation? Most importantly in recognition of these research results, we are led to ask whether public participation is more likely amongst some populations than others. These case studies indicate that a group may be too marginalized or too disparate for researcher-initiated CBPR to be successful. This chapter also raises further questions around the nature of relationships between social capital and the fostering of an oppositional consciousness. Whereas both communities faced pressing issues only one translated this into a focus of group action suggesting that social capital played an integral role to this experience.

Chapter Nine

The Process of Community-Based Participatory Research

When efforts to establish a participatory research project with people living with HIV/AIDS proved unfruitful, I began working with a local senior's organization to establish a participatory project to bridge generational gaps within social housing. Research addressing age-integration within senior's housing is sparse but does indicate the strong role that perceptions of one's immediate neighbourhood have on feelings of safety and security. This body of research is compatible with the social capital literature indicating that individuals who have greater community connections feel safer and suggests that social interaction may be the most important tool for overcoming fear and social distance.

The steering committee's goal for the participatory project was to build social capital as a means of enhancing social connections between residents through the implementation of CBPR. This chapter begins with a discussion of the process through that participation in the research project was achieved and reflects upon the strategies which helped and hindered social engagement. The remainder of the chapter elucidates the experience of community-based participatory research within one housing setting identifying the challenges of its conduct and the paradoxes underlying theory on the subject. Throughout the chapter the voices of participants are drawn on to offer a counter-perspective to the ethnography of the process which I recorded. The chapter concludes by suggesting some strategies through which community involvement may be enhanced but stops short of espousing community-based participatory research as an effective or inclusive means of carrying out research or enhancing local social capital. Indeed, I suggest that the researcher's skills may be better used in collaboration with community organizations pursuing research as part of their mandate, or through other participatory strategies involving less extensive community organizing efforts

9.1 ESTABLISHING PARTICIPATION

The current project was promoted in two age-integrated housing settings both containing 30-40 apartments; residents included seniors and a smaller number of non-seniors (those aged under 65) with disabilities.

9.1.1 The First and Only Meeting with Building A

In November of 2006 this study was promoted within Building A through the use of flyers distributed to individual apartments and a poster pinned to the foyer's bulletin board. At the time of distribution, a group of women using the building's common area were informed of the premise of participatory research and the goals of the initiative; the women explained that they, and others in the building, were very busy and unlikely to have time for such a project. The flyers (see Appendix 4) invited residents along to a community meeting to discuss the project. Residents were also given the option of phoning the researcher directly to discuss the study or to participate in an interview. No one attended the residents' meeting or contacted me with regards to the study.

A number of weeks later, I had a conversation with the manager of Building A in which she stated that she had not expected the residents would be interested in the project as their needs were largely being met, noting that overall the tenants are fairly mobile, and tend to be engaged in activities outside of the building. Implicitly, she connected the likelihood of residents getting involved in the study with their level of unmet need, explaining that those who were not mobile were serviced by existing programs in the community such as meal delivery services, and therefore had no need to instigate social action. Importantly, the manager also remarked that there was a good sense of community amongst the residents in the building and that residents tended to look out for each other by assisting those in need and reporting larger problems. These were comments which were in conflict with reports I had heard from a local housing advocate and a social worker both of whom had been made aware of increasing social difficulties within the building; problems which, anecdotally, had been connected with the growing age differences amongst tenants. With no opportunities to make social connection with residents or upcoming building meetings at which the study could be promoted efforts to initiate a participatory project within this housing setting were abandoned.

9.1.2 Introduction to Building A

Promotion of the participatory research project within Building A met with more success, in part, because an opportunity provided by the organization to promote the study at an annual meeting of the building's residents and the board of directors. The meeting was extremely brief so, conscious that I not drag the meeting on too long, I spent approximately five minutes introducing myself and explaining why I wanted to carry out research involving the community. The residents appeared to grasp the concept of community-based participatory research immediately and began suggesting issues they felt needed to be addressed before I had even finished explaining the nature of the study. At the forefront of issues concerning residents were services provided by the local parallel transit service and the lack of activities available for youth in the area. Residents were quick to voice incidents involving the parallel transit services and the threat posed by youth, particularly vandalism. I asked the residents interested in getting involved in a project to contact me and handed out flyers to everyone in attendance. A week later I went back and put flyers next to the doors of all residents.

After the meeting ended, one resident, who held a prominent position within the building, spoke to me quietly and suggested that he would go around and knock on doors and get a group of three or four people together to work on the project. He went on to explain that many of the residents act like children complaining about things one day and refusing to talk the next. I was placed in the difficult position of having to explain, before the project had even begun, that I was hoping to gain the cooperation of as many people as possible and one of the goals of the project was to foster cooperation amongst residents. While participatory research is intended to be flexible to accommodate the needs of a community, the ideal of inclusive participation remains at its foundation leading to concern that this resident’s desire systematically to exclude some individuals from the project would meant those who might benefit most from being involved would not get the opportunity. The following week I was told that this resident, due to family commitments, would be unable to take part in the project. I suspect that had he been involved, the project would have been a very different experience due to the pre-existing authority this person held within the building and the tendency for other residents to defer to him. Later comments by other residents confirmed that there was some frustration with the dominant position this individual held within the building.

9.1.3 The First Project Meeting

Word of the project spread quickly through the building, suggesting social capital had a strong role to play in establishing interest in the participatory research project. The ‘initiative’, however, was being talked of in terms of a project to address the parallel transit services. This was evidenced by a conversation I had with a bus user while distributing flyers and later with an interview participant whose community organizing efforts had centred on presenting the project as an opportunity to take action on the parallel transit service (see Appendix 5 for more details about the parallel transit service study). This process speaks to the emergence of an ‘oppositional consciousness’ which Robinson (1999) sees to be integral to the achievement of social action. Without the early identification of the parallel transit service as an important issue, it is highly doubtful that the community would have mobilized to participate in the study. It was also on the strength of the issue that three of the participants who attended the first group meeting were users of wheelchairs/scooters and another individual used a walker.

Establishing a personal connection with residents had the effect of encouraging attendance at the subsequent project meeting. During initial attendance at the introductory meeting and on another occasion when I visited the building I had the opportunity to talk to a number of residents one-on-one and many were very positive about the project and promised to call. Making these connections, I believe, helped bridge the insider/outsider dualism and fostered an interest in what the project could achieve. While only one individual had contacted me to organize an interview, seven people attended the first project meeting and the majority of these were individuals with whom I had spoken to one-on-one at the resident/board meeting.

The initial study plan was to carry out interviews with stakeholders (those community members who indicated a long-term interest in involving themselves in the project) through which research priorities could be identified. One interview was carried out prior to the first project meeting; however, at the meeting the remaining stakeholders indicated an aversion to the interviews with one respondent suggesting that there was little point in taking part in interviews when all of them felt the same way and had the same things to say. Given that interviews are most useful in situations where capturing the breadth of experiences and opinion is a priority, the stakeholder was probably correct in anticipating that little could be gained from interviews that would not emerge through a group discussion. While the decision to be flexible with regards to the interviews compromised the data available as a basis for evaluating the participatory project, this was only one goal of the interviews and was not a sufficiently compelling reason to pursue interviews against the wishes of the group.

Pushing my own agenda at this stage of the research process was also likely to compromise the participatory nature of the project and would add a dimension of self-interest which, I was concerned, might alienate some of the stakeholders. It would also have indicated irresponsibility as a practitioner of participatory research. Throughout the ensuing discussion, it was clear that the stakeholders knew each other well, many having lived in the same building for years, and appeared to have no reservations with regards to expressing disagreement with others' views.

At the first project meeting, it was emphasised that the researcher's role was as a facilitator and that any leadership position initially occupied would hopefully diminish over time. It was also explained that the researcher was committed to seeing the project through to the end of the research stage, and that the non-profit I worked with would continue to be a resource and a network available to stakeholders even after the project was complete. That the non-profit seniors organization was able to provide this form of continued support for the residents was of significant benefit to the unpredictable time component associated with participatory research and the high likelihood that I would be leaving the city in less than a year following the completion of my PhD.

At my prompting, a discussion emerged focussing on the issues most affecting the stakeholders and that could form the basis for a participatory research project. This discussion required a moderate level of facilitation in order to make connections between the individual stories stakeholders told and the macro-level community problems at hand. Out of the discussion emerged three major community issues: the poor services and limited funding for the parallel transit service, lack of activities available for seniors, and the misbehaviour of youth in the area. It was decided by the stakeholders that while the problems with youth (including the paint-bombing of resident’s windows) were significant, seniors’ issues had been largely overlooked in the past and they felt it was time that resources were invested in their own social activities.

In discussions, participants also portrayed a lack of connection between the neighbourhood at-large and their community. Many participants talked of being involved in activities over the other side of town and being gone all day so the youth were not a problem for them. At my suggestion, it was agreed that participatory research would be used to investigate the concerns stakeholders had regarding the parallel transit service and that other means would be employed to address the lack of social activities for seniors in the area.

9.2 PROGRESSION OF THE PROJECT

The community determined that Monday evenings were most convenient for meetings and participation, at least initially, was very high. As the project progressed, a number of difficulties emerged with regards to establishing meaningful community involvement in the research process and meeting attendance.

9.2.1 Achieving Meaningful Community Involvement

Early on in the participatory process during a discussion around project leadership the stakeholders described their desire that project meetings be a social activity, an occasion through which stronger connections could be made with each other as a substitute for the lack of social activities in the building. Stakeholders voiced their desire that meetings be light and fun – stating they would not want to attend a meeting where somebody was telling them what to do. These views were somewhat concerning given the difficulty of making progress on a project where nobody takes the lead.

A similar situation was experienced by Low et al., (2000) when carrying out participatory research with a group of women with multiple sclerosis (MS). Their project combined participatory action research with the formation of a support group which led to mixed understanding of the group’s purpose. As a result the researchers were more focussed on the research and action roles of the group whereas the women were more interested the social aspects of the meetings (Low et al., 2000). While no misunderstandings were evident amongst the Building B stakeholders those who had more invested in the issue at hand were more active in talking about and working towards action. For the other group members the meetings became an opportunity for networking and were a social forum.

Consistent with the stakeholders' desires that meetings be a social occasion, the consensus was that rather than looking for someone to lead the meetings and allotting individuals specific roles, such as a note taker, the stakeholders preferred to be equal contributors. This desire for an egalitarian group appeared to arise, at least in part, as a response to resentment over the way that past activities in the building had been dominated by a small number of people who had long periods of tenure. The inadvertent result was that rather than being an impartial facilitator I had to take a much stronger role in moving discussions forward and pushing the project agenda than I had envisioned (see meeting notes below).

> **Sarah:** So we're going to look into [another residential facility in the study city] and try and get some sort of a relationship going there. And [another stakeholder] is going to look into the local church activities.
>
> **T:** Yes, I'll be talking to [...] probably by the weekend, so, [...] when and how...
>
> **Sarah:** So how are you feeling about the progress that we're making?
>
> **Several women:** Good!
>
> **U:** I think we're going to do okay. To get things out in the...
>
> **S:** ... into the open...
>
> **U:** ... into the open, yes...
>
> **Sarah:** Does anyone here read[local weekly newspaper], or...
>
> **U:** Yes, we all do...
>
> **Sarah:** ... [the daily local newspaper] ?
>
> **U:** The Substandard you mean, not the [daily local newspaper]!
>
> **Sarah:** So maybe if you could keep an eye out for any articles on the [parallel transit service], because I don't read those newspapers often, so that would be helpful if you could keep track of things.... And maybe if we work on getting people together for a series of focus groups, then, once if we write a report we can give it to ... the "Substandard".
>
> **U:** Yes, we could put it in the Editorial or the ... people's column or whatever...
>
> (Excerpt from second CBPR Project Meeting, 27th November, 2006)

Throughout the participatory process, the researcher must remain astute to the extent that their input is needed in the group process. The participatory approach I was aiming for works toward maximising empowerment amongst the research stakeholders through active engagement in the research process which usually involves the researcher initiating the research and having an ongoing role managing the research process (Cornwall and Jewkes, 1995). I viewed the position of the researcher more as a facilitator whose role would decline in importance over time as the community gained the knowledge and skills with which to play the role themselves. In reality this was very difficult to achieve.

Participatory research, at least in theory, involves a very strong element of teaching as the practice of research is conveyed to stakeholders and the tools to carry out research themselves provided. One of the challenges of participatory research is facilitating stakeholder use of newly acquired research skills. What makes this process complex is the assumption that stakeholders will continue to take a leading role in decision making and implementation of a research project despite never having employed these skills before and being in the presence of an ‘expert’. Furthermore, in this instance the group did not want to take the leading role. There was a clear desire for social action and frustration with the status quo, but this was not being turned into action, potentially because of my presence as the instigator and thereby the person who should take control (see Tandon, 1996).

Different strategies were employed to enhance stakeholder involvement. Initially, I tried to encourage stakeholders to work on the project in their own time For example, at the first meeting I translated the stakeholder identified priorities into a set of achievable tasks we could work on for the next meeting and encouraged the stakeholders to take responsibility for some tasks in the intervening time. At my suggestion, the stakeholders agreed to look at the social activities occurring in other senior's buildings, while I was to make contact with the manager of the parallel transit services. I saw this as an easy way to begin making a contribution as many stakeholders had friends living in nearby buildings who they could talk to and nobody had been willing to talk to the parallel transit service manager. The stakeholders had not pursued this task and at the next meeting I began to look toward achieving more at the meetings rather than asking stakeholders to do 'homework.'

9.2.2 The Second Project Meeting

> Even where a community appears well motivated, dynamic and well organized, severe limitations are preserved by an inadequacy of material resources, by the very real structural constraints that impede the functioning of community-based institutions.
>
> (Cleaver, 2001:46)

A further challenge to the participatory research process was the difficulty of coordinating meetings. The evening was deemed the most convenient time to meet because many of the stakeholders had health conditions which necessitated frequent medical appointments. By this time of day, many of the stakeholders however, were getting tired and we often sought to keep meetings as brief and lively as possible. This became even more challenging in January and February 2007 when influenza and hospitalizations were affecting the most active stakeholders and a number of meetings ended with stakeholders appearing visibly fatigued. Knowing that it was difficult to get the stakeholders together and concurrently tackling limited energy levels put pressure on meetings to be effective in a very short period of time. This experience was common to

Low et al., (2000) for whom discussions regarding the fatigue associated with MS made the researchers reluctant to overburden participants.

The energy and time of participants was a particularly pertinent issue when the task involved was something that I could complete in a relatively short period of time (such as writing a research proposal) whereas the stakeholders, for whom the task was novel, would require substantially more time to complete it. The most active stakeholders involved in the project were also users of wheelchairs and scooters, so while I would have liked to invite them to the non-profit offices to work on the project outside of meeting times the difficulty of getting downtown and the inaccessible nature of the office prevented this. These physical barriers, I believe, also reduced the ability for the project to enhance networking as stakeholders were unable to make connections with the non-profit as an organization.

At the second project meeting a participant had requested I make a poster to promote Bingo within the building, a strategy to increase the dwindling number of attendees, and a directive I resisted out of concern that a precedent not be set whereby I became the primary worker on the initiative. Instead, after the next meeting I worked with two individuals who had professed a desire to learn computer skills. We created a poster to advertise the Bingo carried out on Tuesday nights. The point of the poster was to inform those living in other seniors buildings of the event and thereby extend the social activities available to residents on a reciprocal basis with other buildings. This process was greatly appreciated by the two stakeholders involved despite the challenges of learning to use a computer particularly a lap top given the vision challenges the stakeholders had of which I had been unaware.

9.2.3 Fluctuating Involvement

Meetings, usually held on a fortnightly basis, were established and carried out throughout November and December of 2006. The early meetings were divided socially between users of the parallel transit services and the seniors who felt the bus services were inadequate, but were not users. The latter group was more interested in the meetings as a networking occasion and had more stake in extending the social activities available within the building than addressing the parallel transit service issue. This was a division which became spatialised during the meetings as those with wheelchairs and scooters dominated one end of the room and those using chairs the other leading to parallel conversations focussing on very different issues. Concerned that the non-disabled would lose interest in the project, I raised this possibility with the parallel transit service users that we may have to work hard to keep everybody interested by focussing more on the social activities. Very soon after this suggestion; however, those who were not parallel transit service users declined in their attendance at the meetings and by February 2007, there was only a core group of three-to-four people attending the meetings, almost all of whom were parallel transit service users.

The efforts to simultaneously pursue CBPR on the parallel transit service issue and promote senior’s activities within the building began to backfire just before Christmas. After producing a Bingo poster we pinned it to the communal noticeboard. The stakeholders later told me that the idea was met with great resistance from the other building residents who were not involved in the project as it invited residents from other senior’s housing buildings to participate. The more established residents were uncomfortable with outsiders coming into the building and had removed the poster. This experience was upsetting for those stakeholders involved and appeared to be a preceptor for the declining stakeholder attendance at future meetings. At this point we abandoned our attempts to encourage social activities and focus on the parallel transit service though there were side-effects for the CBPR project, as noted in the quote below:

> There was people that started to come then dropped back. Now the one thing I find very sickening about that is somebody - as soon as they found out that, they were key to the meetings in the first place, and then when they found out that this other group of people were pretty against them doing anything well then all of a sudden she tried not to be at the meetings. I'm like that's not very nice. It just is not the way you do things, but it's like anything else. You try to get meetings going from here to there and then people here will be complaining about having them over here and then people out there were saying they didn't want our people over there, so I mean what the heck and when you can't get somebody in this building to walk downstairs to play Bingo you sure as hell aren't going to get out there to a meeting.
>
> (Final interview with stakeholder 'Y')

Disappointment at the attendance levels at meetings was a common complaint voiced by stakeholders at the regular meeting. They often lamented the reluctance of other residents to leave their apartments singling out the older residents (those in their 80s and 90s) as choosing to distance themselves most from the social activities of the building. When asked to suggest reasons for this declining attendance, the remaining stakeholders felt it was not a problem of a lack of interest in the parallel transit service, but a symptom of the apathy of the resident body as a whole. On another occasion, the absence of a regular attendee was explained by a dispute which had occurred between him and another stakeholder over an issue unrelated to the project.

> B: "I think we're going to have to work hard to get people involved in here, because, like I said, there's a lot of people in here who just don't want to come out of the apartment and get involved in anything..."
>
> (CBPR project meeting, 27 November, 2006)

While the group was initially made up of residents of Building B, stakeholders were told that it was their project and they were welcome to bring friends along to the meetings.

One stakeholder took the initiative of inviting a friend to join the project. The friend had been heavily involved in accessibility issues with a local hospital and was keen to take action on the parallel transit service. This individual had been more active politically than the other stakeholders, a position that somewhat influenced the group dynamic as stakeholders identified her as being the most capable and therefore willing to take on more responsibility. The addition of this stakeholder took place at a point in time when others were choosing to leave the project making her presence particularly timely given the toll attrition was taking on the morale of stakeholders

9.2.4 Meeting Guests

The stakeholders were keen to have special guests along to the meeting who were involved in pertinent issues. The first of these guests was the executive director of the parallel transit service. He was invited along to explain the booking process for the parallel transit service and what went on behind the scenes. This was a way for the group as a whole to gain more information about the issue at hand, to establish a discussion on the goals of the project, and the political implications of criticizing a local government-funded service. The executive director was very successful in portraying to both the stakeholders and myself the difficulties of providing parallel transit services on a finite budget and suggested that the provision of the service was never going to meet demand. The organizational criticisms group members laid upon the executive director, specifically, the tendency for the service to use separate buses for people going to the same place fifteen minutes apart, were acknowledged by him as being shortcomings of the service which should not be happening. The executive director committed himself to looking into the number of instances in which this problem occurs and to report back to us with the outcomes of his investigation; he never reported back to us.

The discussion with the executive director did not dissuade the stakeholders from the need to look into the parallel transit services, many having information about the individual which preceded our meeting and created cynicism regarding his commitment to improve the service. Some of the statements the executive director made were in direct contradiction to information stakeholders had been provided by others involved in the service and their own experiences using the service. A significant concern was with regards to the executive director's argument that the parallel transit services had a policy of equal access for all regardless of where the individual was going. The stakeholders had consistently had difficulties booking buses between 8am and 9am due to their use for transporting children to school and this led to many cancelled appointments.

> "...but at that general meeting that [executive director] told us one thing and it was a direct lie and I damn-near called him on it, but 'R' said something to me and I answered her and by that time he had gone on to something else, but it was a lie. And I thought oh yeah, you mucky mucks and you get everything covered up and what's the little guy gonna do about it? Nothing."
>
> (Excerpt from final interview with 'Y')

Early in the participatory process, the stakeholders talked of raising awareness of their problems with the parallel transit service amongst city councilors and specifically their local councilor by inviting these individuals along to a meeting. This was a significant move in the context of the participatory research project because it indicated that participants felt their concerns were deserving of attention and there was sufficient support within the stakeholder group to pursue action. This enthusiasm did, however, pose a problem for the participatory research process, as it omitted the research stage and went straight to the action!

Later a similar issue arose with another stakeholder. Having recently learnt that the parallel transit service had received little media attention, the stakeholder suggested this avenue might lead to some results. She also stressed the importance of getting numbers behind us to achieve change on the basis that past efforts had been unsuccessful and gaining the support of those in prominent places might lead to a more positive outcome. Without these factors, she felt it unlikely that any real change would happen. These were ideas that the stakeholders supported and we moved forward by listing all of the organizations which could support out initiative. We went on to discuss the research process in more detail and the stakeholders came to their own conclusion that the media and the public support of these organizations would best be sought once the research results were forthcoming.

As the research process got underway a disability advocate and parallel transit service user contacted me about taking part in a focus group. This was somebody a stakeholder had already suggested would be an asset to the group so I invited her along to a meeting to educate the stakeholders and myself of the politics behind transportation for disabled persons in the study city. Prior to the meeting, I suggested to the stakeholders that they invite her to attend future meetings should they think it worthwhile. The stakeholders later indicated to me that they *did* want her involved but they did not invite her back and I was left to organize this.

9.3 PUSHING THE RESEARCH AGENDA

Entering into the research process, there was a very real possibility that the stakeholders would identify an issue of concern for which there was no need for research. The parallel transit service was a problem where research could contribute substantially to our understanding of the issue at hand and provide a clear trajectory towards action. This point was communicated to participants by explaining that the views of three-to-four people might not have as much weight with newspapers and city council as a study which explored the experiences of a group of parallel transit service users. The perception of research in wider society was also discussed in the context of the weight given to 'scientific' views versus general public opinion. I raised the possibility of using research to investigate the extent of difficulties, and positive experiences, of the parallel transit service by using focus groups. The stakeholders indicated general agreement with the focus group idea. I had only briefly discussed the option of interviews and made the suggestion that a quantitative approach would not be ideal in this context because statistics already collected by the parallel transit service would render any data we collected to be of a lesser quality. Later, I realized I had overstepped the bounds of the participatory format by not encouraging participants to evaluate actively the benefits of the different research approaches. In large part, my actions were motivated by a desire to make some progress on the project and retain the attention of the stakeholders who were restless and getting tired.

9.3.1 Establishing a Research Plan

Having pushed the idea of focus groups, at the following meeting I backtracked and discussed other research options which included a survey approach, interviews, and focus groups. This education process was intended to ensure stakeholders have the skills to evaluate research alternatives themselves at a future date when I would not be available. I had an important role in explaining research methods to the community, and ensuring the stakeholders are educated in the methodological options available for the decision making to be a collective process (Freire, 1970). After some discussion of the costs and benefits of the various research alternatives focus groups were agreed on by the stakeholders as a means of collecting data. This decision was based on identifying focus groups as an effective way of drawing out opinions and experiences through the interactive component. The stakeholders felt the parallel transit service study participants would get more out of the research by incorporating this element of social interaction. While the group reached the decision to use focus groups themselves, it is possible that my initial support for this approach may have influenced their decision. To assist in working through the research process a progress road map was developed (see Figure 9.1).

The study plan was developed using a collaborative process where I asked stakeholders to define issues such as the goals of the study and who they thought should be eligible as participants. Throughout this process, I explained the implications of their decisions on the shape of the potential research outcomes and took notes which would later form the research proposal. The stakeholders had been reluctant to choose a note taker suggesting that none of them would stay on task sufficiently well. I believe this was detrimental to the process because it became more difficult for participants to see the direct connection between their ideas and the form the research proposal ultimately took. For example, it was decided that participants would be recruited through advertising and posters at supportive agencies and through word of mouth. The stakeholders identified a series of questions to be asked of focus group participants, these included:

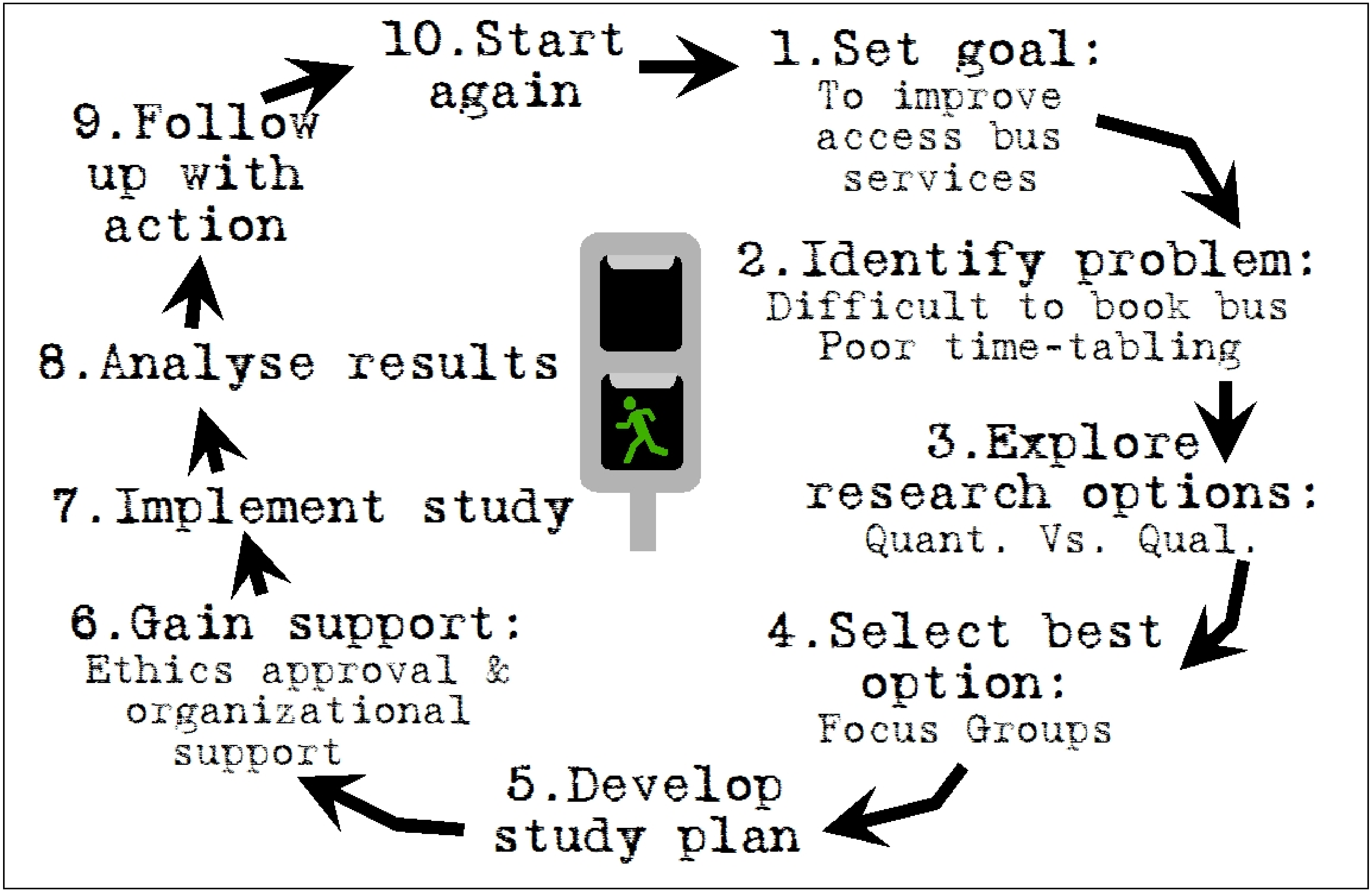

Figure 9.1: CBPR Progress Road Map

(a) How much does the service cost bus users weekly and how much of that cost is reimbursed by ODSP?

(b) How flexible are the bus services? Can changes in medical appointments/ late bookings be accommodated?

(c) How efficient are the bus routes taken?

(d) How well coordinated are the bus services?

(e) What are your views on the quality of customer service offered by the bus?

Following feedback from the parallel transit service and other stakeholders, these questions were modified to encourage greater discussion of personal experience and formed the basis for the focus group questions, see below:

(a) Please discuss why you began using the [parallel transit service] and what other transport options are available to you given your financial situation and your mobility.

(b) What financial cost do you face through use of the [parallel transit service] in an average week and how does this affect your budget? If you receive ODSP please also explain to what extent your transport costs are covered by the government.

(c) Does the flexibility of the bus service impact on your daily activities (e.g., what happens when you have changes to medical appointments, last minute meetings etc.)?

(d) Does the efficiency or coordination of the bus routes impact on your use of the bus service? Prompts: in terms of timing of buses, collecting multiple passengers, etc.

(e) What are some of the other strengths and weaknesses of the service you have experienced that we haven't already discussed?

The stakeholders were concerned about bus users bemoaning the service in private but being unwilling to go on the record with their complaints. This problem was likely to be due to either a fear of repercussions or a sense of apathy and the prevalent attitude that nothing is likely to change regardless of what they do or say. To counteract this problem, we emphasized the study's independence from the parallel transit service and emphasized that the study was user-driven. I spoke to stakeholders about the importance of confidentiality and anonymity in research and explained the nature and purpose of research ethics reviews. It was decided that in order to enhance outside perceptions of the research as 'valid' the study would be submitted for review to the university ethics committee. I spoke about the importance of assuring all participants that anything they say in the focus groups would be kept confidential and no names would be used in any resulting publications. The research proposal was later approved by the Queen's University General Research Ethics Board, see Appendix 6.

A strong theme which arose throughout the project meetings was the importance of looking into parallel transit services in other cities, particularly in nearby cities where participants were aware that the same problems were not being experienced. I proposed that one aspect of the study should look into the approaches used in other cities by interviewing key providers and making recommendations regarding how the city's service could be improved. This was something the stakeholders were very agreeable to and was included in the study proposal.

9.3.2 Participation in the Data Collection

I suggested to the stakeholders that given their experience and understanding of the focus group topic that they would be effective facilitators of the groups. The stakeholders did not voice any overt agreement to this suggestion, but did identify the stakeholder most involved in community affairs as the most appropriate person to facilitate the focus groups. Aware that this individual would be in hospital in January and was already taking on a lot of organizational responsibility for the group – and perhaps had less to gain from the facilitator role than other participants – I suggested we conduct a training session whereby all stakeholders have the opportunity to learn about focus group facilitation and those that felt comfortable and capable at the end of training could choose to adopt the role. This was met with agreement on the part of the three stakeholders present.

The training of stakeholders took place over the course of a two hour meeting and was challenging due to a range of health conditions affecting energy levels; two stakeholders had only recently been released from hospital. During the training session a mock focus group was used as an opportunity to discuss some of the social issues prevalent in seniors' and disabled persons' housing, a topic which was embraced by the stakeholders. Stakeholders were provided with focus group scripts which included introductory statements and the focus group questions they had identified at an earlier meeting. While the training session was not as thorough as I would have liked due to the low energy levels of stakeholders, I was confident the two volunteers would have no problem facilitating the focus groups as both were very personable, capable and confident that they could do the job.

Having stakeholders trained in focus group facilitation was only one step of the research process. When it came to organizing the focus groups, other barriers to participation emerged. On a number of occasions we were invited to facilitate focus groups with regularly meeting support groups. I was usually informed of these meetings at the last minute meaning that the stakeholders were likely to be busy and if they could attend at that late notice a parallel transit service was unlikely to be available to transport them.

Compounding this problem were the stakeholder's health issues – most were in and out of hospital while the focus groups were taking place or were not well enough to attend. Some also had trouble scheduling events in advanced because they did not know how they would feel on the day. These are not isolated problems but issues which affect many people living with disabilities and works systematically to disempower and steal their voices.

Of the six focus groups carried out, two were facilitated by stakeholders (See Appendix 7 for more details). The stakeholders successfully distanced themselves from the emotive end of the discussion and thereby avoided influencing the focus group participants' views. When asked directly by a participant how they felt about the parallel transit service, one stakeholder avoided discussing her opinion by explaining that her experience had 'been very different' from the woman's who asked the question. Both stakeholder facilitated focus groups were scheduled for the same day as a strategy for cutting costs and reducing the effort on the part of stakeholders. Toward the end of the second focus group, it was, however, clear that the stakeholders were getting tired and I began facilitating in addition to taking notes.

9.3.3 The Analysis and Interpretation of Research Data

A great deal of thought was given to the most appropriate participatory way of analyzing and interpreting the findings of the focus groups. While a software programme for qualitative data analysis may have been more systematic, I saw little benefit to the stakeholders in learning to use this new tool. This intervention, on my part, was intended to maximize participation in the analysis by overcoming limited computers skills and vision problems experienced by some stakeholders. My actions may, however, have been perceived as disempowering as I did not give stakeholders the opportunity to make this decision themselves. Instead, we used the opportunity of a project meeting to filter through the transcripts and identify common themes. Only two of the stakeholders participated actively in this process despite approximately five people being in attendance at the meeting. Aware that this may have been due to social pressures I asked stakeholders to continue reviewing the material in their own time and asked during subsequent phone calls and project meetings whether further themes or issues had been identified.

At a later date, I systematically coded the transcripts and cross-checked my coding with the themes identified by stakeholders making only minor adjustments due to the high degree of consistency. This strategy was intended to provide stakeholders with the opportunity to participate in making sense of the data without bogging them down with paperwork (See Appendix 7 for more details).

9.3.4 Writing and Disseminating Research Results

The power over research publication has traditionally lain with the researcher and funder who often create obstacles to the dissemination of results through delays in publications and in the choices they make regarding where they publish (Whitehead, 1993). Community-based research puts an end to the impetus for research findings to be distributed primarily within the academic realm. The stakeholders may decide to use a community forum as a means of educating the public of the research results. They may also decide to use flyers, media promotion or some other forum which is widely accessible to a large group of people. Research results may also be disseminated to government organisations and policy makers to persuade those in power of the need for community change, and may in fact be a component of the ‘action’ stage of participatory research.

The action stage of the research began with the publication of a blurb and photograph about the study in a newspaper supplement produced annually by the collaborating non-profit. This was followed by the annual general meeting of the parallel transit service which three stakeholders attended in addition to myself and the president of the non-profit with which I worked. All of us present raised prepared questions seeking explanations for inadequacies in the service provided. This process was pivotal for the stakeholders and was raised by them in the final interviews as an opportunity for their voices to be heard despite frustrations with the management of the service. The dissemination of the research findings and publicizing of the study took place following the conclusion of the project evaluation; however, the stakeholders and I had assistance from those involved in media relations to plan strategies for getting the project disseminated as widely as possible.

Publication of results in academic journals may be pursued in which event the stakeholders will at the least have an editorial and advisory role in these documents. This, for example, was carried out by Potvin et al. (2002) who successfully negotiated authorship in a participatory research approach by establishing a community advisory board whose ongoing management role extended to disseminating research results, contributing to conference presentations and academic publications, in addition to being co-investigators in the grant. A similar scenario will be carried out in the present research with the research stakeholders involved in determining guidelines for assigning authorship.

9.4 ANALYSIS OF THE CBPR PROCESS

Participatory research and, more generally, activist research, emphasises the importance of achieving a genuine commitment and engagement with the community: "The combination of research and activism requires a commitment for the long haul, the need to immerse oneself in the community situation and more connection to the community than most researchers have" (Kobayashi, 2001:63). Carrying out participatory research in the context of an academic degree, however, places a fixed time frame on the research process which is incompatible with this open-ended commitment and has the potential to undermine the sense of continuity.

> A doctoral student working on a dissertation cannot afford the luxury of working with a community on a community's timetable and with the possibility that the project will be called off or take on a different set of goals – in fact, become a different project. Financial considerations and doctoral committees conspire to impose rigid controls on the student's proposal, research, and its allowable conclusions, all of which not only inhibits community participation in the project, but effectively prohibits community control over the outcomes.
>
> (Heaney, 1993:45)

Within participatory research literature, a discourse of commitment permeates and researchers are encouraged to distance themselves from traditional research approaches where one goes into a community, collects data, and leaves again. Carrying out participatory research in the context of an academic degree makes this practice very hard to implement because the transitory nature of postgraduate students may undermine a sense of continuity or, alternatively, lead to the imposition of a tighter timeframe on the project. While my research timeline may have impacted on the project the most pressing influence for me was the desire that the stakeholders achieve tangible outcomes at a pace which prevented loss of interest. The stakeholder's own level of commitment to it was much more open-ended with a general view that the project would be an ongoing engagement from which they would withdraw only if they moved.

9.4.1 Identifying a Study Issue

Collaboration at the early stages of a participatory research process establishes a sense of community ownership over the project. It also provides the opportunity for those affected by the research to interact with the process, to influence the topic being studied, and the approaches being adopted to ensure the research is of relevance to their lives (Vingilis et al., 2003). It is, however, rare for the community to have a clearly defined problem to address when entering into participatory research as this would require an initial level of collective organisation (Freire, 1970). The researcher plays a part in facilitating the identification of a problem and the direction which may be taken to address the issue: “The researcher works with the community to help turn its felt but unarticulated problem into an identifiable topic of collective investigation” (Freire, 1970:9). Minkler and Hancock (2003) recommend listening in on the ‘private discourses’ of a community to identify the issues which they feel most need to be addressed; this is based on the assumption that individuals themselves can make the greatest contribution to understanding their own experiences (Low et al., 2000). During the project, the addition of an already established disability activist was integral to shaping both my own and the other stakeholders’ understanding of accessibility issues in Ontario. Her knowledge of the key organizations we needed to deal with made the project easier and boosted the overall confidence of the stakeholders, and myself, of what the group had the potential to achieve.

An area of concern going into the research process was that the research topic being negotiated with the community fit with the interests of health geography. I defined this as being specifically, a concern with elucidating the impacts of our environment on the health and wellbeing of individuals and populations. It was deemed necessary that the research be compatible with the focus of health geography for two reasons: first, through my Ph.D. I am required to extend knowledge within the discipline and hoped to make a genuine contribution to the sub-discipline; and secondly, a more practical necessity was that research be within the bounds of my own expertise for me to contribute valuably to the process. Entering the research process I was concerned that the realm of health geography might appear too abstract to the stakeholders; however, the early identification of the need for a project focusing on access for persons with disabilities, a topic of considerable concern to health geographers and geography in general, made the need for a discussion of health geography and the limitations of my own expertise unnecessary.

9.4.2 The Role of the Researcher

Importantly, adopting participatory research requires redefining the role of the researcher as a partner in the production of research, as one who works with communities to solve problems and achieve collective action (Park, 1993). The researcher brings to participatory research a set of technical skills which may become secondary to her role as instigator of the research, facilitator, mediator, and observer of the group process; however, balancing these multiple roles can be challenging. The researcher must be aware of the nuances of the group and adjust his/her role accordingly. But most importantly the researcher must not control a situation and must be flexible to the direction the group adopts (Muelenberg-Buskens, 1996). This requires a level of self-awareness and necessitates constant self-reflection on the impact the researcher's presence is having on the group process. I found it easiest to draw from my set of technical skills in my efforts to position myself as a facilitator rather than a leader. I emphasized that while I had the research skills the stakeholders were posing the problem for examination and it was their direction which was fundamental to its momentum. The stakeholders, in turn, positioned themselves as the 'voices' of the project. As the process, however, progressed, I found myself doing less facilitation, more sitting back and listening as the stakeholders took discussions in new directions which were more critical of the role of government in facilitating accessibility, and looked at what else the group could achieve.

Working with people who are on fixed incomes and are coping with multiple health conditions led to a feeling of helplessness in my role as a facilitator and researcher. While we were working to address an important issue affecting people with disabilities many other sources of difficulty emerged in the lives of the stakeholders and were a focus of much discussion. The inability of one stakeholder to gain home care support following an operation and the frustrations another woman felt at getting no traction with a committee she was serving on, and the sheer loneliness she felt led to an emotional meeting at one point. As Kobayashi (2001:57) notes: "The ethical questions involved in overtly activist research are many. How does one negotiate between a specific social objective and the need for verifiable knowledge? How does on deal with the inevitable emotional aspects of working with people whose circumstances may require immediate attention?" My response was to contribute in small ways, such as, asking if I could bring anything when I came to the meeting or by exploring other strategies for community involvement. Ultimately, these contributions were inadequate and I felt that regardless of what we achieved through the project larger problems that were beyond our control would remain.

A final challenge to my position as researcher was the sense of taking advantage of the participation of stakeholders for the purposes of my own research. While the stakeholders entered the process understanding that I was evaluating the CBPR approach this was an abstract notion and the details of what I was evaluating were difficult to explain. Like Low (2000) in the quote below when going to a conference to discuss the participatory research process some stakeholders had questions about what I was going to talk about in my presentation. The process of participant observation becomes complex as relationships develop with the 'subjects' of the research and dilemmas emerge over what is appropriate to be recorded and what is too personal. While I have erred on the side of caution refraining from discussing the personal characteristics of stakeholders, I am aware that the way I represent the project and how I portray the stakeholders may have an impact on the project itself, through I've tried to avoid circumstances such as that which Low et al., (2000) found themselves in:

> When one of the participants learned that an article discussing the focus group was being prepared for a conference she became extremely upset, asking why she had not been informed, why she and the other women hadn't been asked for their input, and what else was being done with the data. She clearly felt betrayed saying that she had been very proud of the part that she had played in producing the report, and now she was being treated as merely a subject for research, 'a guinea pig' (in her words).
>
> (Low et al., 2000:37)

9.5 SUMMARY

Participatory research is an ongoing journey of reflection, education and action. Throughout the process, events are reflected on and changes implemented accordingly.

Even the process of actualising social change may lead to further questions which, in turn, may be addressed by the stakeholders. In this sense the success of a participatory research initiative may be determined as much by the empowerment achieved amongst individual stakeholders as the actual research outcomes and accomplishment of social change. Indeed, the usefulness of the researcher's contributions may only be judged in future years when the effects of the participatory research become clear, and community participation continues without their presence. Participatory research is not about following a formula, rather, the researchers, participants and study design must be flexible to incorporate change and limitations.

It is virtually impossible to define a clear end to participatory research, but there must be a point at which the researcher's active involvement ceases. Education throughout the research process should be aimed at ensuring the participants, and future research, does not depend on the presence of the researcher: "We are even tempted to say that the best proof of the researcher's success is seen when the group takes charge of the process which has been set in motion by the researcher." (De Oliveira and De Oliveira, 2001:58) An end to the proposed participatory research initiative will come when the research meets a community determined conclusion – whether this be the successful implementation of social action, or a decision to disband the collective action initiative.

Chapter Ten

Outcomes of the Community-Based Participatory Research Process

The evaluation of the CBPR social housing case study was carried out prior to the final results of the parallel transit service study being publicized. This occurred due to the thesis deadlines I was facing and the process itself extending much longer in duration than I had hoped. The project's timeline was extended due to the longer-than-anticipated process of recruiting volunteers for the parallel transit service focus groups, the hospitalization of three stakeholders (some on multiple occasions) and the competing demands on my own time. It is widely acknowledged that participatory research requires long periods of what may be very intensive community involvement (Kindon, 2000). The difficulties I faced time-wise in establishing a CBPR case study and seeing it through to completion are illustrative of the challenges of working a community-driven project into the fixed timetable of a researcher (in this instance driven by the need to complete a PhD in four years). That is not to say that it is unrealistic to complete a CBPR case study within the bounds of a doctorate but that grassroots community mobilizing is a time consuming and unpredictable process best implemented outside of the PhD process.

I anticipated that completing the project evaluation prior to the conclusion of the CBPR would lead stakeholders to be more reserved about the impact of their work. This anticipation proved unfounded as some of the stakeholders had already witnessed positive outcomes which they attributed to the project. The stakeholders also conceived of the study as part of a larger initiative to address accessibility issues and tended to look at our achievements as part of a broader picture. Whereas the stakeholders may have discussed at greater length the specific achievements of the project had the evaluation been carried out at a later date, instead the interviews were an opportunity to reflect on the less tangible benefits of being involved in the CBPR process.

This chapter focuses on three aspects of the research outcomes: learning and critical consciousness, empowerment, and community change. I draw primarily from the final interviews with the four most active stakeholders to explore what was learnt from the project and how it impacted on their lives. The low number of stakeholders most active in the process as it neared its conclusion means that the data sources in this chapter are limited to those individuals who remained central to the research process and thus were in the most informed position to comment on its successes and weaknesses.

10.1 LEARNING & CRITICAL CONSCIOUSNESS

In Freire's (1970) model for what might arguably be termed emancipation, he outlines a process for raising the critical consciousness of the most marginalized individuals in society. His focus on those most economically and socially disadvantaged is based upon the potential he saw for raising their critical awareness of the structures that oppress them. I critique his simplistic distinction between the oppressed and the oppressors in Chapter Two, section 2.2; a criticism that deepens when the final stakeholder interviews are analysed. Freire's categorization of the oppressed is a distinction based almost entirely upon class. There is an inherent assumption that the majority of those who are oppressed are not critically conscious: "The basic premise of social action models is that disadvantaged people must be empowered, organized and educated if they are to summon the psychological will, skills and organized group support ... requisite for social action toward a common cause” (Kar et al., 1999:1435).

In the discussion below, I distinguish between what stakeholders learnt from their involvement in the CBPR process and the raising of critical consciousness. The learning process includes both the practical skills attained through involvement in the research as well as knowledge gained about the lives of others who are ‘oppressed.’ Critical consciousness is a subtle process involving a change in perception as a result of what is learnt. The extent to which a critical consciousness is assumed to be lacking amongst the ‘oppressed’ is questioned.

10.1.1 Learning from the CBPR Process

Stakeholder learning from the CBPR process was concentrated in terms of new knowledge regarding the lives of others with disabilities. Practical research skills were not amongst the learning resulting from the research process.

Emerging out of the final interviews with stakeholders was how much they learnt about the needs of other people with disabilities from being involved in the project. Early project meetings had focused on individuals sharing their own experiences accessing basic services and dealing with the parallel transit service. As the process unfolded, these discussions extended to include accessibility challenges facing others with a range of disabilities, the role of local government in facilitating access for persons with disabilities, and the implications new provincial legislation aimed at increasing accessibility might have at the local level. In the quote below ‘R’ discusses what she learnt about others experiences with disabilities from being involved in the project.

> **Sarah:** So what have you learned from being involved in this study?
>
> **R:** Well, that there needs to be a whole lot more done for handicapped people. There's so much that needs to be fixed. It's not just the [parallel transit] Buses...everything.
>
> **Sarah:** So your perception around disability issues might have been changed a little bit?
>
> **R:** Oh yeah. Yeah. A lot.

Early on in the research process discussions were focused on personal experiences. This dynamic shifted when ‘Z’ joined the group and informed everyone of strategies for dealing with particular disability related issues, such as booking the parallel transit service and maintenance of the stakeholder’s wheelchairs. The group was very diverse with respect to how long individuals had been using wheelchairs, ranging from 1 to 12 years which extended to impact on levels of existing knowledge regarding disability issues. ‘R’, for example, stated that she had “never been involved in anything like this before so its been a good experience.” It should not be surprising then, that ‘Z’ who had been using a wheelchair for the longest time and was most involved in disability activism learnt the least about the needs of others with disabilities. ‘Z’ felt that she was already knowledgeable about the challenges affecting persons with disabilities and knowledge gained from the focus groups was minimal:

> **Z:** I don't know if I learned anything new, but it certainly reinforced what I know is going on and that is there are parts of town in [the study city] that gets less service from [parallel transit service]. How you solve it, I'd like to know. I'm trying to figure that out. I mean if you're up in the north end of town, there's no medical appointments up there. That actually might improve and change depending on what stores go up in the north end by [] street. They're going to build some stores up there...I think there's supposed to be a big Canadian Tire, a couple things like a Wal-Mart..

The fact that some stakeholders were more knowledgeable of the experiences and needs of persons with disabilities in the study city was an asset from which both I and the other stakeholders benefited from as they shared their knowledge. Gaining the involvement and support of those more active in disability issues had the effect of, not only facilitating group learning, but of boosting the group's confidence regarding what could be achieved and the obstacles which stood in the way of reaching the group's goals. There was also a mutual benefit in that 'Z' enjoyed the social nature of the project "just meeting up with other people is so important for me, so vital."

The individual most active as a disability advocate was less critical of the parallel transit service, however, this did not appear to affect the other stakeholder's appreciation of her involvement or their own opinions regarding the parallel transit service, as the transcript excerpt below illustrates in response to a question about the parallel transit service focus groups:

> **R:** Well, I found them quite interesting and ['Z'] is quite interesting and she has a lot of information....Well, I don't mind sitting and listening to her because I think you could learn a lot from her.
>
> **Sarah:** Definitely. Definitely. Yeah, she's amazing. I think it was great that she got involved with the project.
>
> **R:** Yeah. It's too bad that there wasn't more people like her around and we'd probably get a little bit further.
>
> **Sarah:** Yeah.
>
> **R:** But, like I said, I think something has happened with the [parallel transit] service because they are getting a little bit better and hopefully they'll continue to.

Diversity of experience within the group was a clear benefit to the learning process and perceptions of what could be achieved. This finding has two major implications: first, it reinforces the importance of bridging forms of social capital as facilitating group achievement. A group which is too similar or too insular is less conducive to the process of social change as acceptance of the current situation may be engrained and the connections to resources that facilitate action are less likely to be forthcoming (unless the group is already relatively powerful). The opportunity for new stakeholders to join the group, bringing with them different sets of knowledge and skills, was a benefit to the participatory process and speaks against establishing CBPR in the setting of a closed group.

Secondly, the learning process adopted within the study speaks to the peripheral role the researcher can play within the CBPR process. While the researcher may be fundamental in getting the process started, they are no substitute for the presence of established activists. In many respects, the current experience speaks to the importance of transferring the social mobilization role to the community where their own social connections and local networks may facilitate participant recruitment. The process of social mobilization is an evolving one which, while facilitated by the researcher in this instance, is largely dependent upon the group's social relations. Establishing these kinds of community-based networks takes time, time which may be beyond the schedule of the researcher.

Interestingly, when I asked stakeholders what they learnt from their involvement in the process none identified research skills in their answer. The reasons for this are likely a combination of their light involvement in research activities (i.e, had they been more heavily involved in coding the data or writing the research proposal, they might have learnt more) and the lack of practical relevance the research activities had for their daily lives. Stakeholder involvement in the research process was reduced for a range of reasons (discussed in greater detail in Chapter Nine); most significant were the multiple health conditions which constrained participation. The stakeholders were very aware of their limitations and often voiced them (e.g., by requesting meetings not take place on a day when they will be tired from too many doctor's appointments) and this was a strong factor affecting both the kind of roles they took on and the extent of their time investments. It was also a source of stress for the stakeholders as in many instances they would have liked to have been more involved but were restricted by their health conditions. As 'Y' indicates below:

> **Y:** Now, I would have liked to have someone to go to these [focus group] meetings... so you didn't have to do it all yourself, but health-wise, as I say, that's one of the things that I'm putting myself on a regime because I never know and like I might go down and nothing happens, but I also know myself and I also know that within a month I can go down with the blink of an eye and then, you know, you feel bad because you're invited to go down and you just don't hold up your end and there's not a thing you can do about it. And it does, it makes you feel bad because I gave my word...I gave my word and I feel that I should be able to uphold my word. So, I find that difficult...

While the research process was 'owned' by at least some of the stakeholders (evident in discussions of 'the study' that 'we're' doing) the research skills themselves were not something the stakeholders identified as belonging to them or in any way central to their lives. This finding appears to emerge out of faulty assumptions of CBPR that stakeholders will benefit from carrying out research and *need* to carry it out themselves to achieve a level of critical consciousness and to work toward social change themselves once the researcher is no longer involved. These assumptions undermine the resources and intelligence of the community who, at one of our final meetings, recognized the value of drawing from my own social networks to connect them with another researcher (e.g., another graduate student) with whom they could carry out further research without needing to apply those skills themselves.

10.1.2 Critical Consciousness

Achieving a critical consciousness is a function of understanding the social processes contributing to oppression and is largely tied to what is learnt through the research process. It may be understood as the cumulative learning solidified into more critical awareness of how one’s place in the world is produced. Reflecting the study’s focus on disability issues, stakeholders recognized their increased awareness of inaccessibility as systemic to society and a function of widespread ignorance, the failure of many other people with disabilities to speak up, and political and economic forces concerned with the cost and time involved in making the city, and even spaces heavily used by disabled people, accessible.

> **R:** ...I think you'd have to do a lot of talking because some people just don't understand it...the stuff thats got to be done for handicapped people. Like there's two stores out here and they're corner stores...well, one corner store and then [] - that's a meat store, but they sell other stuff - you can't get into them because there's no ramps anywhere and they want our business but....And the little corner store here that sells everything, I can get into the front door of the store, but that's as far as I can go.... Well, I don't think there's going to be any solution unless people get more aware of what the problem is and I don't think that's going to happen right away.

In the final interviews, all of the participants raised at some point public ignorance toward the accessibility needs of disabled persons. The stakeholders also shared a level of cynicism over how effective efforts to increase accessibility will be while there are so many negative attitudes in the wider public. This issue was also articulated a number of times in project meetings through discussions around the frustration of having to ask for help and the reluctance of members of the public to make life easier for persons with disabilities (e.g., by making room on a bus). These discussions reflected a critical awareness of the systemic forces that hindered accessibility for disabled persons. The stakeholders were aware that while we could fight for organizational or institutional change, specifically through lobbying for improvements to the parallel transit service, until the attitudes of the broader public undergo change accessibility would remain a problem, as the quote from ‘Z’ below illustrates:

> **Z:** I don't know what you do. I mean I have the perfect example of that when I was on the VIA Rail and I said to the guy: Look, I'm tied to the floor to the train. I need to be able to push a button to alert you guys when you're in the serving area of the train that I gotta get into the washroom and to have him come back and say to me, well if you want to be treated equally you gotta bring someone on the train with you to undo the straps...they're not allowed to undo the straps if I bring someone on the train. That has to be done by them. So, I'm bringing a person on the train to go and get the guy out of the server to then come and undo my straps? Well, frig, then I gotta pay for the guy to be with me - or whoever I take with me - gotta pay for their accommodation all weekend when I don't need him for anything more than that? No, you put a doorbell in or like a wireless doorbell that I can alert the guy and then when his line is do you want to be treated equal the same as everybody else...well, same as everybody else is not the same in what you're talking about, you know. I mean, yes, I can be the same as everybody else, but the reality is I use a wheelchair. I'm tied to the floor of the train because of the legislation from the government. The other people aren’t tied to the train seats; they're not dependent on VIA Rail to go to the washroom, so that's where the equalness[sic] comes from.

The same stakeholder conceived of the failure of members of the public to respond to the needs of persons with disabilities as a function of social and economic pressures. She argued that stress associated with financial instability and other symptoms of modern life lead people not to look beyond the needs of themselves and their own families:

> **Z:** There isn't enough focus on just working together with each other and just being, being community-based. You know, the ice storm was wonderful in the fact that is brought a lot of good out in people. When the ice storm happened there were so many people who had no power, a lot of people were trapped in their buildings because there was no auxiliary power to run the elevators to get people out of the buildings. Then they ended up putting all these temporary shelters up and you had volunteers coming out of the woodwork. I mean everyone just seemed to be attuned to the needs of others. And it's the same you've seen with Katrina and with the Tsunamis and all this stuff, but when you don't have a disaster of that sort...everyone's like...how many people do you see talking to their neighbours? Ice

> hockey...or road hockey...I think they've been trying to bring it back, but it's been taken off...it's not allowed in _____at the moment. Well, if you can't play and you're sitting there doing everything individual at home and you're stressed out.

There was little doubt in my mind at the completion of the research process that the stakeholders were in possession of a critical awareness of disability issues. This was not an awareness founded upon academic discussions of equity or a discourse of political correctness but on the lived experiences of the constraints and challenges of living with a disability on a daily basis. The stakeholders possessed a rich understanding of where their challenges derived from and their need to act for anything to change. What was less evident was the importance of the CBPR process in achieving this critical consciousness.

Discussions with stakeholders revealed a significant amount of variation with regards to the role of the CBPR process in shifting their perceptions of disability issues. Those stakeholders who were involved in the process from the beginning, and had been previously politically inactive, stated that their perspectives had changed as a result of their involvement in the process. The experience of those who were already active as disability advocates indicated that they had learnt less from the CBPR experience.

Drawing from social capital theory, it should not surprise us that those who became involved in the project at a later date were already socially involved. The fact that two of the stakeholders were already disability advocates intuitively means that they were further along in the awareness process and had less to learn from their involvement in the CBPR process. Their higher levels of engagement may also be related to seeing themselves as being in a better situation than many others, due to their increased mobility or spousal support, although they still faced numerous challenges to participating in mainstream society.

10.2 INDIVIDUAL EMPOWERMENT

Measuring empowerment is a considerable problem for the evaluation of social action initiatives, one which requires responsiveness to the individual experiences of a group (Flynn et al., 1994; Laverack and Wallerstein, 2001). Measuring the concept is complicated by the fact that the empowered outcomes, and even the process, is likely to be unique to the specific group context and social setting (Zimmerman et al., 1995). That empowerment may fluctuate is a further factor leading Zimmerman et al., (1995) to conclude that a universal measurement of empowerment is not viable:

> The measurement of PE [psychological/individual empowerment] in a specific setting for a particular sample of individuals is possible, but it must be connected to the experience of the research participants as *they* state it, and contextually grounded in *their* life experiences. This approach necessarily limits one's generalizability to other persons or contexts, but we may have to accept this trade-off in order to adequately and appropriately measure PE.
>
> (Zimmerman., 2005:596)

Fundamental to evaluations of empowerment is the distinction which must be made between community empowerment and individual, or psychological, empowerment. Individual empowerment "integrates perceptions of personal control, a proactive approach to life, and a critical understanding of the sociopolitical environment" (Zimmerman, 1995:581). Individual empowerment is a component of community empowerment sitting alongside factors such as participation, leadership, social capital, critical consciousness, and program management to shape empowerment at the group, or community, level (Laverack and Wallerstein, 2001). Community empowerment and 'empowered outcomes' are discussed in section 10.3 Community Change.

Individual empowerment is a fundamental goal of the CBPR process achievable through the acquisition of knowledge, experience, and a critical consciousness. In the CBPR process empowerment is thus distinguished by an increased discourse of control over problems in the lives of stakeholders, an increased commitment to addressing issues of concern, and an increased belief in their ability, including in the context of the group, to achieve social change. This point of social connection is stressed by Zimmerman (1995:582), a pre-eminent empowerment theorist: “PE [psychological empowerment] is not simply self-perceptions of competence but includes active engagement in one’s community and an understanding of one’s socio-political environment.” Clearly there is a close relationship between empowerment and critical consciousness discussed in section 10.1.2, critical consciousness being one aspect, or perhaps a step, in the process of becoming empowered. This discussion will concentrate on perceptions of control and ability to act to address issues of concern within one’s life.

The CBPR stakeholders were slow to raise the issue of empowerment in interviews. Rather than ask the question directly (for fear of coercing a positive response), I asked such questions as ‘what did you learn from the process’, ‘how do you feel about our ability to achieve change’ etc. What became apparent throughout the course of the interviews was that the stakeholders were taking greater ownership over the problems at hand and had an ongoing commitment to social change. Over the course of the research process, and most markedly after the project group stabilized in numbers, the stakeholders depicted a clear commitment to the research process. This was most evident when I showed up to a meeting and was told about their plans for me to look into the accessibility of shops once the current project was complete “*we’ve* got the next problem lined up for *you*.” Evident in this discourse were the stakeholder’s issues, or ‘their’ problems, becoming ‘my’ project a reflection of the modest level of participation achieved through the day-to-day research activities. Another stakeholder who joined the project at a later date indicated a lesser control over the project and a number of times indicated that *I* should look into broader accessibility issues.

The stakeholders were quick to acknowledge that our presence had produced some change in terms of the parallel transit service (discussed in greater detail in Section 10.3) but they were less ready to describe the group as capable of achieving positive change. When I asked questions on issues such as their satisfaction with what we had achieved, many of the stakeholders were quick to point out the difficulties of achieving change particularly in the face of strong political forces. This awareness of those in positions of power, such as the executive director and board of the parallel transit service, or city councilors, was a strong issue running through the project frequently described through a sense of helplessness.

> **R:** I don't think so. It would be nice if the people at the Parallel transit service would realize that we know what we're talking about...the problems that they have and trying to do something about fixing them, but like I said, the service is getting a little bit better so maybe they've got wind of what's going on and maybe they're trying. That would be nice.

Finding that the parallel transit service had improved in terms of both availability and customer service was a major boost to many of the stakeholders and confidence in what we could achieve grew as a result. The stakeholders were quick to discuss anecdotes of improved availability or customer service and noted that they believed it was due to our project that the parallel transit service was improving.

> **R:** And now I don't know whether the [parallel transit service] has heard about the study that we're doing. I phoned yesterday morning at 7:30 because I had to meet a doctor over at the [hospital] emergency and I got a bus.

> **Sarah:** Wow! That's amazing. That never would have happened a couple of months ago, would it?
>
> **R:** No, it wouldn't have. So I think they must have an inkling of what's going on.
>
> **Sarah:** Right.
>
> **R:** Because the service seems to have got better since we've started the study.
>
> **Sarah:** That's interesting, isn't it?
>
> **R:** Yeah because it was never that easy and I can phone in two or three days before an appointment and I can get a bus and I could never do it before and appointment and I can get a bus and I could never do that before.

Stakeholder involvement in the process went through a number of changes over the course of the project with those less affected by the issue at hand ceasing involvement, as discussed in Chapter Nine. In the final interviews, I raised with stakeholders how they felt about the group. The responses I received were very positive with regards to the individuals involved in the project and the nature of their personalities. The stakeholders indicated that there was a high level of agreement and general cohesion but there were concerns voiced about the need for more stakeholders and particularly individuals with a high level of initiative or leadership. One particular stakeholder (quoted below) talked at length about the need for leadership after I explained the original project group had ruled out the need for a leader. Her comments below came only a few days after a phone conversation in which she voiced her appreciation of the hands-off way that I had facilitated the focus groups allowing everyone to talk was something she contrasted with the over-regulated way another committee she sat on was run.

> **X:** You've always got to have a leader. You've always got to have a leader; someone that can organize and help organize. Now, what might...I don't know where you are on timeline now, but I mean one thing that could be done in the future is if you were to go with that goal you've got, I think it's a good one, but then I think if you've got the leadership part of it, what a leader does is not only help steer the direction of your focus groups but then you could also work at delegating and you could also find out - you could say okay this is what we want to do and we want to do this as a conjunctive project so okay who's got a computer here that can

> help us help coordinate this and go look at and help do the typing of the report. But try to assign tasks. Do it on a voluntary basis.

'X's' comments reflect, at least in part, the dynamic process of participatory research and raise the need for the goals and functions of the group to be reassessed regularly as stakeholders turnover and new members with new skill sets emerge. My decision to honour the initial statements of the stakeholders likely became outdated as most of those individuals left the group.

The process of empowerment did not run along traditional lines as the process of the stakeholders' involvement as researchers and leaders was somewhat sidelined. It was clear that a sense of empowerment was fostered through the research process as evidenced by the attribution of improvements to the parallel transit service due to the group's efforts, renewed commitment to the project, the identification of new issues to address, and levels of critical consciousness. Remaining, however, was a cynicism regarding how the likely effectiveness of the efforts of so few in the face of strong political powers.

10.3 COMMUNITY CHANGE

Community empowerment has been found to take in excess of seven years to achieve and is evident in such experiences as changes to government policy (Raeburn, 1993, as cited in Laverack and Wallerstein, 2001). As a long-term process derived from learning and the attainment of a critical consciousness, the experience of community empowerment is unlikely to be realized until after the present study comes to a conclusion as it tends to involve a process of personal empowerment, connections with small mutual groups, the establishment of community organizations and partnerships and, finally, social and political action. “The potential of community empowerment is gradually maximized as people progress from individual to collective action along this continuum” (Laverack and Wallerstein, 2001:182).

> **Y:** Now, I can tell you something that happened yesterday that is definitely new... [R]'s bus - remember it was supposed to pick her up yesterday morning since she had to leave so early to get to the hospital to wait for her appointment. Well, it was late and it was late because the bus that was going to get her was involved in an accident on the 401, but [R] so anyway (I think she was about a half an hour late), when she came home yesterday from the hospital and checked her answering machine, [a parallel transit service employee] was on the answering machine and she profusely apologized to her for the bus being late and she hoped she wasn't late for her appointment and the reason the bus wasn't there was because it was involved in an accident. And I said to her, I said well boy, we must have made a difference because -- they never would have done that.

The most surprising finding when evaluating the participatory process was the fact that two of the four stakeholders already saw positive change coming out of the project through the improved services provided by the parallel transit service. The stakeholders also saw the potential for further positive change as we worked with the study results and pursued further disability related issues. There was, however, some level of conflicting opinion as one stakeholder saw the potential for us to achieve change on the individual level, for example by educating parallel transit service users with regards to service provision (see quote below) whereas the other stakeholders focused on the need for public attitudes to change or the need for those in power to become more responsive. This difference may be attributed to the later stage at which Z joined the project when the study goals had already been established or her less critical attitude toward the parallel transit service.

> **Z:** I think it could have a lot of positive impacts. You look at the results there that you've put out there. I mean you've got the transcripts now and, as I've said earlier, you've got parts there that...basically there's just people there don't remember the rules or rules have changed a little bit, so you could take that, build

> on that and what you could do is help inform people and so you have...you determine okay some of this is just a matter of misinformation so let's go right away and make sure everyone's informed and maybe that means going to Parallel transit service and saying as well that you know we did this...all this input stuff, we realize a whole bunch of people don't know about some things that exist.

Where stakeholders were unanimous was in their belief that being involved in the project had been a worthwhile activity. The general feeling amongst stakeholders was that while they may have faced some inconveniences in attending meetings (e.g., due to health difficulties and transportation problems) their investment of time and energy was well placed. A major part of why they saw their involvement to be worthwhile was because of the potential for others to benefit as a result of what we were doing, as the quotes below illustrate:

> **Sarah:** And in terms of the time and the energy that you've put into this project, what do you think about the costs of being involved versus the benefits. Has it all been worthwhile?
>
> **R:** Yeah, I think it's been very worthwhile. I mean, like I said, I hope things continue to get better. We could sure use more better stuff happening.

> **Sarah:** Has it been worthwhile for you?
>
> **Y:** I think so. Yeah, I really do. As I say, we needed the numbers, not as high as we'd like it to be, but I think that we have made a difference. Maybe some small difference, but...
>
> **Sarah:** And it's not over yet.
>
> **Y:** That's right. That's right. So it's...yeah, I think we did well. I really do. -------- We at least tried, you know. Like, don't sit back and complain about things if you're not willing to try to make a difference and we did at least try so...And, as you say, it's not over yet. Maybe somebody'll turn around in mid-stream and really make up their mind that they want to do something about it.

Emerging as a particularly interesting finding from the research was that although the stakeholders felt their time was well spent and that their work had led to some positive change with regards to the parallel transit services, they did not see their work as having any positive *social* impacts within the social housing or disability community. This is consistent with the argument that social change takes a number of years to achieve. The stakeholders identified a number of reasons for this but predominant was the attitude amongst the wider community that their efforts were not likely to come to any good. Also identified was the fear of repercussions for speaking out and simply a lack of interest in the issue at hand.

> **Y:** It is so hard to get older people interested in something and like I found that it was almost as if people didn't want to really speak about anything that was really negative about them...almost to the point where you got the feeling that they were afraid that they wouldn't have the bus if they spoke up and there are so many questions that were brought up at the general meeting and the different answers we got, like there was, I felt and the reason I didn't say all that much that night, was because I felt that the president that was speaking there...I felt that he...like he wasn't open to anything negative like he had an excuse right ready and it just you know I...and with the people that were there, I felt well, we're not going to get any place even if we do open up and say what we feel.

Stakeholder 'R', responding to a question about whether the community had developed as a result of the process, discussed those residing in her building who dropped out of the research process: "Well, I don't think we did out here – I don't think we did too much of anything out here." There was considerable frustration amongst the stakeholders that, socially, their efforts had made so little impact. This frustration reflects an awareness discussed in Chapter Two that CBPR is as much about participation and fostering social cohesion at the community level as it is about empowerment and the learning of skills at the individual level.

10.4 SUMMARY

The process of community based participatory research works toward goals of individual empowerment, critical consciousness, practical learning and community change.

Discussions with stakeholders central to the present CBPR case study indicated that they were benefiting from involvement in the project and, in large part, their understanding of the needs of people living with disabilities had been extended and they had a clear conceptualization of the societal and political processes that stood in the way of achieving an accessible city. It was clear, however, that those who were less involved with disability issues prior to the project beginning gained more from their involvement in the study than those whose involvement preceded the project. Interestingly, even those who were actively involved, however, were able to gain from the group dynamic of working together and making the most of a social occasion despite their modest expectations of what we could achieve.

I will briefly refer back to a quote from Chapter Two where Weininger (2005) draws from Bourdieu to assert that the social dynamic in itself is not enough to achieve social change, rather there must be a considerable amount of work to overcome the social and political challenges that stand in the way of an improved world. Much of this work (Weininger, 2005) is at the symbolic register and requires the visible mobilization of a group to act on behalf of others similarly oppressed. The combined impact of the group's collective voices at a parallel transit service annual general meeting and the publicizing of the study in an annual newspaper supplement may just have been the symbolic events that led to improvements in the parallel transit service. Regardless of how small the group is, it appears that positive social change may occur. The practice of extending social change into the wider community, however, is much more difficult to achieve and requires, in addition to the investment of the labour which Weininger (2005) references, a considerable amount of time. Community-based participatory research draws on stocks of social capital but this is a process which may also highlight deficiencies in social capital when investment and commitment to a CBPR project varies over time.

Chapter Eleven

Conclusions

Two years and three case studies after my first efforts to initiate community-based participatory research, I am working with a group of stakeholders to turn our research findings into positive action. Throughout the process, I have become infinitely more aware of the challenges people with disabilities face in the study city and more generally in society. I have reached a new understanding of the conditions which enable an idea for social change to become a reality. I have had the opportunity to work with a group of women who were able to educate me about their lives and, despite their health conditions and disabilities, committed themselves to the project. They worked through the challenges of declining participation and concerns over our insignificance to see the potential good that could come out of it.

I begin this conclusion by reviewing what I have learnt about the process of community-based participatory research and how the process could better meet the needs of communities given the findings from the three case studies. I then take a more critical turn to question the assumptions upon which CBPR is based and how consistent these are with the goals of the process. Noting the failure to achieve intensive community involvement in all stages of the research, I then take a look at the key outcomes of participatory research (conscientization, empowerment, and social change) and discuss how central research was to their achievement. Before discussing the limitations of the study I consider where academics fit in the scheme of CBPR and where the future for academics and participatory research might better lead.

11.1 THE IMPLEMENTATION OF CBPR

The discussions within this thesis are founded upon social capital theory and Bourdieu's conceptualization of the social and symbolic structures that shape society. These social relations have the potential to divide or unite groups within society but tend to act along social and economic lines distancing those who are educated or wealthy from those at the other end of the spectrum. Often in unconscious ways we act to distinguish ourselves from those groups who we deem to be different from ourselves. At its most extreme this is termed 'symbolic violence' by Bourdieu (1992) as we stigmatize and exclude those who are different from our lives. This practice was evident in the unsuccessful CBPR case study with people living with HIV/AIDS where widespread social stigma had permeated within the group to form a layered stigma creating even further artificial divisions which compromised the power of the group as a whole. Coming up against this kind of engrained social distance was too big a challenge for researcher-initiated CBPR to overcome and speaks to the value of developing long-term relationships within a community before implementing a project.

At another level social capital was seen to be fundamental to the success of CBPR by bridging relationships with gatekeepers, which allowed me to work with those marginalized groups who would be difficult if not impossible to contact otherwise. Gaining gatekeeper support is not, however, an easy task particularly in a sector where employees are over-worked and already vulnerable to criticism. Establishing a positive relationship with a gatekeeper organization is facilitated by long-term involvement with an organization, the use of social connections, and clear communication. The support and commitment of a gatekeeper group can determine the success of a project as the creation of opportunities to meet with potential stakeholders in a positive environment may vastly improve the likelihood of success of a CBPR project. Due to these later findings, I have no regrets over walking away from the organization where support was not forthcoming and would recommend others to do the same if caught in a similar situation.

11.2 THE RESEARCH IMPERATIVE

The practice of CBPR is founded on the assumption that stakeholders can acquire research skills which will enable them to challenge future sources of oppression. In implementing CBPR, I aimed toward a co-learning level of participation in which I would collaborate with the stakeholders to plan the project, implement the research, and work toward social change. Decisions were to be made primarily by the stakeholders and I was to be a source of research skills and facilitation. The level of participation achieved, however, was much closer to a relationship of cooperation (see Figure 2.1) where priorities were determined by the community stakeholders, but the force behind the research remained with me as I was responsible for the bulk of the organization behind the project, ensuring the research happened, and creating momentum.

There was a significant period in which our roles were being negotiated because CBPR was new to both myself and the stakeholders. I initially sought stakeholder involvement in all aspects of the research, but quickly realized that there were activities they had little interest in (such as writing a research proposal) and that using meetings to discuss ideas would be a more inclusive way of structuring the project. As time went by and many of the able-bodied individuals dropped out of the project numerous health and accessibility related barriers came to the fore and prevented intensive involvement in the research process. In response I prioritized the focus for stakeholder participation with those research skills most useful to everyday life (primarily the facilitation of focus groups, the planning and decision making surrounding the project, and the analysis of the research data) rather than pursuing ethical applications or the writing of reports which they opted not to participate in. The rationale behind this ensured stakeholders saw the relevance of the project to their daily lives and did not get overwhelmed by the detail of research.

Much of the participatory research literature idealizes community participation and makes the argument that for participatory research to be meaningful stakeholders must be involved in all aspects of the research and learn skills which would enable them to repeat the process in the absence of the researcher (Cornwall, 1996). In carrying out the final interviews with the most active stakeholders it became evident that they did not wish to be involved in all aspects of the research, nor did they see it necessary to their continued activism in the area of disability issues. While it was evident that they saw research as a valuable tool, the stakeholders positioned themselves as spokespersons and idea generators rather than co-investigators in the research process. These roles put the stakeholders at the centre of the problem at hand and allowed them to focus more on the big picture than the details of the research – a strategy which potentially contributes to the conscientization process.

The great majority of the CBPR literature focuses on the opportunities the researcher *provides* stakeholders to participate in research. Frequently cited as a limitation of CBPR case studies are limited opportunities for stakeholder control. This research, in contrast, highlights the circumstances which may limit a community’s ability to get involved and suggests that community collaboration may not be possible in all aspects of the research but that this need not be a shortcoming of the approach. Rather, it may indicate that the goal of community empowerment through research may be misplaced, that there may be alternative strategies for engaging and working with communities that have more resonance with the community itself.

11.2.1 Questioning the Assumptions of CBPR

A hierarchy of participation is evident in much of the CBPR literature which places research driven by the community as the ultimate goal. While criticism of the unattainable nature of pure community-driven research have been made (Maguire, 1997), intensive community involvement remains the panacea for achieving empowerment through participatory research. Interviews with the stakeholders involved in the present research raised two important issues which undermine the assumptions upon which CBPR is founded:

First, the present decline in social capital, discussed extensively in Chapter Four, tells us that amongst the things standing in the way of community involvement are high workloads, long commutes, isolating technologies, and a generation of disengagement. These broader social changes are compounded by the challenges which marginalized groups face in becoming civically active. The stakeholders discussed at length the difficulty of being involved in the research process when hospitalization, multiple medical appointments, and poor health stood in the way. For some participants following up a day of medical appointments with a committee meeting was an exhausting experience and one that they felt hindered their ability to make a meaningful contribution to the meeting. It is a paradox of participatory research that those who might benefit most from being involved in the process are also those who face the greatest barriers to participation. The fact that those individuals who carried on through the process faced many complex chronic health conditions yet did not cease involvement speaks to the value of being flexible in the research approach and responsive to stakeholder's needs. That the group was small no doubt made it easier to schedule meeting times and locations around the needs of those individuals for whom attending meetings was most difficult.

Secondly, the assumption that community members will benefit from carrying out research through their ability to use those skills following the researcher's exit from the scene is fundamentally flawed. The interviews with stakeholders made clear that they were involved in the process of carrying out research as much as they were able and willing to be. While one stakeholder expressed frustration that her health condition prevented her from facilitating more focus groups overall, she was content with her contribution and saw no need to make the process more participatory. Assuming that stakeholders *want* to carry out research in many respects undermines the participatory process as it gives them little choice over whether the project should even involve research and requires they devote time to a process which may hold little relevance to their everyday lives and be of little use to them in the future.

11.3 THE OUTCOMES OF CBPR

Participatory research, as conceived of by Freire (1970), espouses education as a means of conscientization, that is, becoming aware of the social processes which reinforce oppression and thus one's own position in society. An educator, Freire (1970) sees the role of the researcher in participatory research as one who must facilitate the enlightening of the stakeholders, a process achieved by their involvement in transforming their own realities. This understanding of participatory research is translated into a philosophy of CBPR by the likes of Hall (1998) who proclaim the process of involving stakeholders as research co-investigators to be the unifying basis of this participatory strategy. In this respect, CBPR differs from participatory action research and participatory methods where the stakeholders are more likely to be involved as research participants rather than conceiving of ideas themselves.

11.3.1 Conscientization

Despite limited involvement by the stakeholders in the practice of carrying out research, most of the findings from the concluding interviews indicated that a level of the stakeholders possessed a critical awareness of the systemic problems facing people with disabilities. Most participants noted that their perceptions of disability issues had changed over the course of the project, suggesting the CBPR process had a role to play in this awareness. Specifically, when discussing the parallel transit services, stakeholders moved away from identifying the management of the parallel transit service as the primary root of the problem toward an understanding of the role of others in speaking out as a means of changing things. There was a new recognition of the strength of political processes, but an acknowledgement that through voicing opinions things could change particularly where large numbers are involved.

Fundamental to the conscientization process was the involvement of a stakeholder late in the process who had a long history of disability activism. This individual was engaged in local government committees and was familiar with province wide disability legislation. She instigated discussions around strategies wheelchair users could adopt to navigate better the city in general and the parallel transit service. Her involvement extended the breadth of experience and comfort the group had with activism and her energy levels had us all in awe. Her involvement also indicated the extent to which ill-health could impact on stakeholder engagement. While she experienced chronic neck pain this was a minor condition when compared with the health issues affecting the other stakeholders. While Kobayashi (2001) points to the importance particularly of class and gender contributing to diversity, in this instance health was the primary demarcating factor. This woman's long involvement in disability issues and the health conditions which had severely affected her mobility meant that she was still very attuned to the needs of all persons with disabilities. It also meant that rather than being a divisive force, she was fundamental to achieving a consistently critical position in which the participants were a force with a common political direction being that all stakeholders saw accessibility as a right rather than a privilege.

Amongst the pivotal points in the project was the facilitation of a focus group by stakeholders in which a participant voiced her opinion that users should be grateful about the parallel transit service and the failure to see the benefits of it was a function of individual perspective rather than real experiences. This woman's statements in contradicting the position of the stakeholders was a solidifying force in that the stakeholders, as a group, in later discussions rejected her point of view and lamented the fact that so many people with disabilities simply accept the status quo rather than working toward equality.

11.3.2 Empowerment

Empowerment is notoriously difficult to measure and for this reason many discussions of whether empowerment was achieved through participatory research are fundamentally flawed. For the purposes of this thesis, empowerment was functionally defined in terms of an individual's commitment to carrying out actions which may improve their own quality of life. The stakeholders who saw the research process through to the end, illustrated how complex the notion of empowerment in their discussion of the difficulty of achieving real change due to the social and political factors which stand in the way. These individuals, however, also professed a commitment to seeing the process through and were active in identifying new areas where a future project could expand on what they had already achieved.

Most significantly, all of the stakeholders professed the need to continue on with the project but to expand it by looking at other accessibility issues. One stakeholder specifically noted the difficulty of getting into stores, the others suggested a need for a project looking at access for persons with disabilities in the study city more generally. The stakeholders were generous when discussing my own role in the research but also raised strategies for furthering the research without me (e.g., by gaining the help of another graduate student). If we take the success of CBPR to be the implementation of further action without the researcher's involvement, then this project may yet prove to be successful.

Based on my experiences with CBPR, I do not see the ability for communities to become self-sufficient in their activist efforts as a marker of success of the project. Rather, I would argue, success is based upon the ability to mobilize and work toward action. Those communities which draw upon resources of social capital, whether it be through non-profit organizations or connecting with other graduate students, are illustrating as much potential for social change as a community group capable of carrying out their own research. The assumption that community members *need* to become researchers to succeed may even be disempowering when we consider how much more efficient and effective a graduate student might be in carrying out research on behalf of the community.

11.3.3 Social Change

The evaluation of the CBPR social housing case study took place at the completion of the research, but prior to the social action stage was seen through to the end. For this reason, I had anticipated research stakeholders would not feel they were effective in achieving community change and might even have been discouraged by the lack of traction achieved with other social housing residents. These concerns were completely unfounded as two of the central stakeholders had over several weeks experienced significant improvements to the parallel transit service we were studying both in terms of customer service and availability of the buses. This perceived improvement in the parallel transit service was directly credited by the stakeholders to the work that we had done and awareness by the parallel transit service of the project.

Perhaps even more significantly, the stakeholders felt that the work we were doing had the potential to go beyond impacting on their own bus use to impact positively the community at large. Even in the face of frustrations over few people becoming engaged in the process and the difficulty of countering strong political forces, the stakeholders voiced a belief that their involvement was worthwhile and was contributing to some good on a wider scale. I suspect that the belief that one is achieving something for the wider social benefit may be fundamental to the success of CBPR.

11.4 EMPOWERMENT, CONSCIENTIZATION & THE RESEARCH PROCESS

Rather than looking toward research as the panacea for achieving empowerment and conscientization, I believe we need to look toward strategies that enhance the skills community members use on a daily basis, particularly interpersonal skills, which build relationships with others. Within the CBPR literature there has been a blind acceptance of the value of research. We need to examine whether other strategies are better at fostering empowerment and critical consciousness and better understand the connections between social capital and empowerment. It is clear from the present research that the withdrawal of individuals from efforts to mobilize against a given cause is disempowering and undermines the process of social action.

There is a significant gap in the literature regarding how empowerment is achieved through processes of social action A large part of the reason for this gap is the time consuming and unpredictable nature of these kinds of social experiments. In this instance, it took two unsuccessful case studies before a community was mobilized and the participatory research process instigated, yet even with a successful project established, the methods of evaluating empowerment and conscientization had to be modified to address the concerns of the stakeholders. For these reasons, I see the need for long-term participant observation of grassroots social activism to be necessary if we are to gain a better grasp of how community processes contribute to empowerment and critical consciousness.

11.4.3 Where do Academics Fit?

In identifying the need for a better understanding of how empowerment and conscientization are fostered at the community-level, I am quite deliberately leaving academics out of the empowerment equation. My reasons for this are multiple:

First, I see an inconsistency between the open-ended employment of CBPR and academia. While community derived research problems, such as the shortcomings of the parallel transit service in the study city, are socially important issues and might further the position of a marginalized group in society, these problems are rarely original and in this sense do little to extend our knowledge. While others might disagree, I see the primary role of academic researchers to be the furthering of societal knowledge. Addressing the needs of communities is an infinitely worthwhile task; however, this is a role filled by government, non-profit, and volunteer sectors so should academics be replicating this work? To play devil's advocate to my argument in Chapter Four that academics have become more responsive to the power relations embedded in research, the increased adoption of participatory research by academics might be a reflection of the declines in social capital we are witnessing. Increased work loads and reduced leisure time might be leading academics to pursue altruistic activities through their everyday work due to a lack of recreation time with which to devote to volunteer activities. Regardless of the motivations, CBPR does represent a research approach with significant repercussions for the furthering of knowledge. If we disregard the history of research and foster research problems that are purely responsive to community needs, we might just make ourselves redundant particularly given that CBPR does not lend itself to overly theoretical analytical approaches.

Further complicating this discussion is the very fact that the goals of academics have changed. Academics, Kearns and Moon (2002) argue, are as much shaped by neoliberalism as the research subjects they study. The generation of external funding means that participatory research strategies face either the competing needs of an external funding agency or chronic under-funding. Combine this with the need for researchers to produce publications and we see the potential for participatory research to be exploited in just as many ways as traditional forms of research. Naylor et al., (2002) for example, explain that funding from Health Canada necessitated the adoption of a more rigid assessment procedure in their community heart health project and led a number of staff and partner organizations to exit the project due to frustrations that new rules were being set late on in the project.

Secondly, my unsuccessful efforts at establishing participatory research case studies in two settings, with people living with HIV/AIDS and with a disability organization illustrates the difficulties of carrying out this form of community-based research and, specifically, with the researcher taking on the role of community mobilizer. These case studies indicate that social capital cannot be manufactured. Rather, it must come from within a community, and these communities are almost exclusively distanced from the privileged realm of academia. Devoting extensive effort to mobilizing communities is not an efficient way of doing research and in many instances may replicate the activities that social workers are already carrying out. Developing stronger partnerships with social service agencies may be one response to this problem but it also comes at the cost of drawing on what may be the already stretched time and resources of these individuals and brings another element of disempowerment into the research process.

Finally, the assumption that the identification of an issue of concern will naturally develop into a research-based resolution is flawed. In the social housing case study, two problems were identified: the first, a lack of social activities for seniors; and the second the poor services of the parallel transit service. While a research project focused on what social activities are needed for seniors could have been developed, this issue is best dealt with through immediate action and adding the intermediary step of research likely would have alienated the stakeholders. In this instance, we addressed two issues – one through research and later action, the other through action. Implementing participatory research with people living with HIV/AIDS was also complex. The diversity in opinions meant that no single issue for research was easily identifiable and perhaps a process of capacity building within that community would have been a beneficial next step prior to attempting to implement CBPR.

11.5 LIMITATIONS OF THE STUDY

Implementing CBPR was never going to be an easy or straightforward process; however, a number of unanticipated problems emerged which limited the effectiveness of the evaluation procedures. I will focus here primarily on the successful case study as the stalled case studies have already been discussed in-depth. The methods I initially proposed for evaluating the process of CBPR were founded on the assumption that a minimum of eight stakeholders would be sought to participate in the project and with attrition there would still be at least six individuals engaged at the end of the process. The reality was much messier as the majority of the seven individuals who began the process either ceased involvement or were peripheral to the project by time the evaluation came near the end. This meant that the surveys I had designed to be carried out before and after the project’s implementation were no longer useful in indicating change. Furthermore, the number of people who were central to the project at its conclusion were so few in number as to undermine any notion of the surveys being anonymous. This problem also negatively impacted on the final evaluation interviews as rather than drawing from a rich array of perspectives, instead I heard from only the four most active stakeholders. An additional two were peripheral to the process attending occasional meetings, but not actively participating in the decision making process.

The addition of new stakeholders throughout the study created a further dilemma as it was not until the stakeholders were involved in the process for some time that these individuals really understood the goal of what I was trying to achieve in terms of evaluating the process. This led to an ethical dilemma regarding whether I needed to gain the consent of these individuals to carry out participant observation when their involvement might only be short term. Ultimately, they continued to the completion of the project and I was able to explain fully the nature of my own study to them and gained their support and consent.

The second difficulty I came upon was the resistance of stakeholders to particular forms of evaluation. The stakeholders failed to see the need for initial interviews and when it came to the completion of project diaries – an approach which was to balance out my own process of participant observation – none were keen. While I have tried to achieve balance through the use of ‘focus group’ material (i.e., transcripts from portions of project meetings where we reflected on the research process), there is a distinct lack of stakeholder input in my discussion of the research process.

On a broader scale the three case studies in themselves reflect study limitations. The three groups represent heterogeneous populations, which hinders group comparisons.

Secondly, and reflecting the views of Freire (1970) that the oppressed have most to benefit from their involvement in research the three groups are relatively marginalized within society. Case studies may have been established more easily in middle-high income settings where levels of social capital are likely to be higher as individuals have greater resources at their disposal.

11.6 CONTRIBUTIONS OF THE STUDY

This study examined the process of CBPR and its relevance to the sub-discipline of health geography. In doing so CBPR emerges as an approach that fosters social relations within communities by building on social capital, it provides stakeholders with the opportunity to learn and experience individual empowerment from their roles in the project, and it can lead to community change. These case studies highlight the necessity of existing stocks of social capital to be in place for community mobilization efforts to be successful. The research indicates that without these stocks of social capital an oppositional consciousness is unlikely to be realized.

A number of shortcomings also emerged throughout the CBPR process; in particular a disconnect was evident between the respective value the researcher and the community stakeholders placed in the importance of research. As researchers, we must be responsive to the needs of participants and break down the power imbalances which impinge on social science research. Community-based participatory research, however, might not be the ideal way of doing so due to the disconnect between the goals of CBPR and academia. Community stakeholders do not appear to need intensive involvement in the research end of the project to experience empowerment. Nor should we assume that they want this intensive involvement. There are many positive reasons for involving community members as co-investigators in the research process and relatively few negative effects. This does not, however, mean that research is *the* most effective way of enabling empowerment and conscientization in a process of social activism nor does it mean that CBPR is the best practice for researchers.

This research has many implications for health geography. Firstly, the research findings illustrate the difficulty of achieving meaningful participation with individuals who are managing multiple and complex health conditions. Efforts to work with these groups must acknowledge the energy, time, and resource constraints experienced by these individuals as well as the frequent frustrations they experience at not being able to make commitments due to their health. The implementation of CBPR is likely to be more complex in health geography than in other streams within the discipline due to the complications experienced by those whose health is compromised.

Secondly, the social housing case study's focus on the parallel transit service indicates the wealth of research topics upon which health geographers and communities may collaborate. The obscure nature of health geography in the eyes of the broader public need not be a hindrance to CBPR, rather, the possibility for research that is deeply applicable to the social realities of marginalized individuals is a strength of the sub-discipline and a strong argument in favour of the greater use of participatory research strategies. I must, however, frame this finding within the broader discussion of the necessity that we continue to look at ways in which communities may be engaged with academia in inclusive ways, ways which may not include research as a central component to achieving empowerment.

There is still much that geographers in general may contribute to the discussions of CBPR. These case studies raise issues around the nature of social capital, marginalization, and stigmatization in small cities; issues which have been paid little attention until now. The implementation of these case studies within a small city restricted the pool of potential participants and may have had implications for the likelihood of individuals choosing to participate due to the lack of anonymity within a location of this size. Further investigations are needed into the role of scale in shaping landscapes of exclusion, and for influencing everyday community participation amongst those who do experience stigma.

This thesis contributes to a broader understanding of social capital and may be extended through further investigation into the way that networks form during the instigation of community-based participatory research and the evolutionary nature of social networks. On another level, the research connects with literature on the voluntary sector. It signals the need for further examination of the way in which funding and organizational structures of non-profits help and hinder the implementation of community-based research and other initiatives within that sector. Finally, this research may be built on by examining discussions of activism and exploring where the role of the research can and should intersect with communities in working toward social change.

11.7 CONCLUDING COMMENTS

> The participatory research process works toward an ultimate goal of implementing community action. The form which participatory action takes hinges on the continued momentum of the stakeholders in the research process and the findings of the preceding research. Sustaining high levels of community motivation are key throughout the participatory process to achieving real change; and change is likely to be more meaningful where community involvement is high.

(Green, 1986, as cited in Institute of Health Promotion Research, 1995)

Many challenges were met over the course of implementing CBPR challenges within the current research, which forced the end of many case studies before they reached the participatory stage. Overwhelmingly, however, these challenges were a function of the difficulty of mobilizing communities rather than a failure of the CBPR approach *per se*. This research highlights the complex nature of community structures and the importance of social capital to fostering an oppositional consciousness. The case study with people living with HIV/AIDS, for example, was disbanded in response to a lack of critical mass or collective voice but not a lack of need for action. If we focus on the nature of the successful case study in which research was initiated and carried out, and in which the stakeholders felt they were able to determine their own levels of involvement, then we can see that once the hurdle of community mobilization has been overcome then CBPR may be a valuable tool for communities. Community based participatory research is a rewarding way of carrying out research as there are tangible benefits to the community involved both directly, through the achievement of social change (in this case addressing the parallel transit service) and indirectly, in terms of community engagement in addressing sources of marginalization and increased potential to achieve social change.

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Appendices

Appendix 1: Information Sheet and Consent Forms

Letter of Information

For Interview Participants
(Round 1)

You are invited to participate in an interview for a research project titled: "**Exploring the Use of a Participatory Approach to Research in Health Geography**." The research is being conducted by Sarah Lovell, a PhD candidate at the Department of Geography, Queen's University, [study city].

The main purpose of this study is to assess how much the public can learn from being involved in research led by the community, and how effective the approach is as a research tool. To do this I am initiating a project led by people living in social housing. My PhD research will evaluate the community project.

As a part of the research I will be conducting interviews in which I will be asking about your experiences living in social housing. The interviews will be used for two purposes:

1) The interview material will inform my PhD thesis. This research may be published in the form of academic articles at a later stage and the results of the research will be made available to others living in social housing and those providing services in [study city] through public meetings and publications.
2) The themes from the interviews will be used to brainstorm research ideas with people involved in the community-led project.

Interviews with participants are expected to last for approximately an hour. If you are not interested in being involved in the community project there will be no follow-up interview.

There are no known physical, psychological, economic, or social risks involved with the participation in the research. Any decision to participate (or not to participate) will not affect your current or future housing situation.

Participation in the research project is completely voluntary and you are free to withdraw at any point in time during the research and for any reason. You can choose not to answer any question(s) with which you are not comfortable.

You will have the opportunity to indicate whether you want the interviews audio recorded, or if you prefer notes to be taken instead. All information will be kept confidential by not revealing your real name. The interview material will be kept in a locked drawer in a Queen's University office and on a password protected computer.

There is no remuneration provided for participating in this research.

Any complaints or queries regarding the nature or manner of research can be forwarded to the following persons/bodies:

Researcher: Sarah Lovell
Ph: 533-6000 ext. 75721
E-mail: 2sal3@qlink.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

Research Supervisor: Dr. Mark Rosenberg
Ph: 533-6046
E-mail: rosenber@post.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

General Research Ethics Board
Chair: Dr. Joan Stevenson
email: stevensj@post.queensu.ca
tel. (613)533-6000 ext. 74579
Queen's University,
Kingston, Ontario, Canada K7L 3N6

Letter of Information

For Participatory Research Project Participants

You are invited to participate in a participatory research project which will be studied for my PhD thesis titled: "**Exploring the Use of a Participatory Approach to Research in Health Geography**." The PhD research is being carried out Sarah Lovell, a PhD candidate at the Department of Geography, Queen's University, Kingston.

Participatory research allows the community to take a leading role in the development of a research project. Participatory approaches use research as a tool for community change, whether it be as evidence to lobby the government, or as a basis for educating the public. I am initiating a participatory research project to be led by people living in social housing to address an issue of concern to you.

The participatory research project will involve a commitment to regular meetings to identify a research problem, become educated on research approaches and to develop the research project. Following the research project it is hoped that some form of community action will take place to respond to the research findings. The research project will be community-led with myself (the researcher) taking a facilitator and educator role in the process.

For my PhD research I will be assessing how much the community learns from being involved in the participatory research, and how effective the approach is as a research tool. If you choose to be involved in the research project you will be asked to:

- Complete a questionnaire at the beginning, and again at the completion of the participatory project.
- Keep a journal to write about your experiences being involved in the participatory project, these entries can be as regular or irregular as you like.
- Allow the researcher to write about the participatory process; she will detail events at project meetings and the roles of individuals in the progress of the project, this is termed 'participant observation.'
- Be interviewed at the completion of the participatory project to reflect on your involvement (you will be provided with an additional consent form at the time of the interview).

All questionnaire responses will be anonymous. To match up the before and after questionnaires you will be asked to write the same code word on both questionnaires. You will be the only one who knows what this code word is; it will not and cannot be used to identify you.

The information collected through participant observation will be kept confidential by not revealing your real name. Outside readers of the study will not be able to identify you based on the information collected. Other people involved in the participatory project may be able to identify you based on descriptions of roles in the participatory project or personal information you might share with them. You will be free to approach the researcher at any time to indicate if there is something you do not want to be recorded. You will also be provided with a typed copy of material collected through participant observation relating specifically to you. You will be asked if you are comfortable with this material being used in the research and may decline to have any, or all of the information published.

The survey, interview and participant observation material will be kept in a locked drawer in a Queen's University office and on a password protected computer.

There are no known physical, psychological, economic, or social risks involved with participation in the research. Any decision to participate (or not to participate) will not affect your current or future housing situation.

Participation in the research project is completely voluntary and you are free to withdraw at any point in time during the research and for any reason.

There is no remuneration provided for participating in this research.

Any complaints or queries regarding the nature or manner of research can be forwarded to the following persons/bodies:

Sarah Lovell
Ph: 533-6000 ext. 75721
E-mail: 2sal3@qlink.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

Dr. Mark Rosenberg
Ph: 533-6046
E-mail: rosenber@post.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

General Research Ethics Board
Chair: Dr. Joan Stevenson
email: stevensj@post.queensu.ca
tel. (613)533-6000 ext. 74579
Queen's University,
Kingston, Ontario, Canada K7L 3N6

Letter of Information

For Interview Participants
(Round 2)

You have been involved in participatory research where you have been developing a research project to address an issue facing people living in social housing. This research project is being evaluated as part of PhD research being conducted by Sarah Lovell, a PhD candidate at the Department of Geography, Queen's University, Kingston. The research is titled "**Exploring the Use of a Participatory Approach to Research in Health Geography**." The main purpose of this study is to assess how much a community learns from being involved in participatory research, and how effective the approach is as a research tool.

You have already been invited to participate in questionnaires and participant observation. You are now being invited to participate in a final interview to discuss your experience being involved in the participatory project. Interviews are expected to last for approximately an hour.

The interview material will inform my PhD thesis. This research may be published in the form of academic articles at a later stage and the results of the research will be made available to others living in social housing and those providing social services in Kingston.

There are no known physical, psychological, economic, or social risks involved with the participation in the research. Any decision to participate (or not to participate) will not affect your current or future housing situation.

Participation in the research project is completely voluntary and you are free to withdraw at any point in time during the research and for any reason. You have no obligation to consent to this interview because of your involvement in the participatory project. You can choose not to answer any question(s) with which you are not comfortable.

You will have the opportunity to indicate whether you want the interviews audio recorded, or if you prefer notes to be taken instead. All information will be kept confidential by not revealing your real name. The interview material will be kept in a locked drawer in a Queen's University office and on a password protected computer.

There is no remuneration provided for participating in this research.

Any complaints or queries regarding the nature or manner of research can be forwarded to the following persons/bodies:

Sarah Lovell
Ph: 533-6000 ext. 75721
E-mail: 2sal3@qlink.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

Dr. Mark Rosenberg
Ph: 533-6046
E-mail: rosenber@post.queensu.ca
Department of Geography, Queen's University,
Kingston, Ontario, Canada K7L 3N6.

General Research Ethics Board
Chair: Dr. Joan Stevenson
email: stevensj@post.queensu.ca
tel. (613)533-6000 ext. 74579
Queen's University,
Kingston, Ontario, Canada K7L 3N6

Consent Form

For Interview Participants

Exploring the Use of a Participatory Approach to Research in Health Geography

Participant Name: ________________________________

I have read the Letter of Information and have had all questions regarding it answered to my satisfaction.

I am aware of the aims of this research project titled “Exploring the Use of a Participatory Approach to Research in Health Geography” and the nature and extent of my involvement.

I am aware that I can contact the researcher, Sarah Lovell, or the department head, Dr. Anne Godlewska, or the Chair of the General Research Ethics Board regarding any complaints or queries with respect to the research:

Sarah Lovell
Ph: 533-6000 ext. 75721 E-mail: 2sal3@qlink.queensu.ca
Department of Geography, Queen’s University, Kingston K7L 3N6.

Department Head, Dr. Anne Godlewska
Ph: 533-2903 E-mail: godlewsk@post.queensu.ca
Department of Geography, Queen’s University, Kingston K7L 3N6.

General Research Ethics Board
Chair: Dr. Joan Stevenson E-mail: stevensj@post.queensu.ca
tel. (613)533-6000 ext. 74579
Queen’s University, Kingston K7L 3N6

I am aware that my participation is completely voluntary and that I am free to withdraw from the research at any point of time.

I am assured that the researcher shall protect the confidentiality of my identity by not using my name or any other identifying information in the research and keeping the raw data safely in a locked office drawer at Queen’s University

Please indicate if you consent to the following:

☐ I **consent** to my interview being audio recorded.

☐ I **do not** consent to my interview being audio recorded.

Name: ___________________________________

Date:_____________

Signature: _________________________________

Consent Form

For the Community Project Participants

Exploring the Use of a Participatory Approach to Research in Health Geography

Participant Name: ______________________________

I have read the Letter of Information and have had all questions regarding it answered to my satisfaction.

I have attended an information session or had a phone conversation with the researcher who has explained in detail what the community project is likely to entail.

I am aware of the aims of this research project titled "Exploring the Use of a Participatory Approach to Research in Health Geography" and the nature and extent of my involvement.

I am aware that I can contact the researcher, Sarah Lovell, or the department head, Dr. Anne Godlewska, or the Chair of the General Research Ethics Board regarding any complaints or queries with respect to the research:

Sarah Lovell
Ph: 533-6000 ext. 75721 E-mail: 2sal3@qlink.queensu.ca
Department of Geography, Queen's University,
Kingston K7L 3N6.

Department Head, Dr. Anne Godlewska
Ph: 533-2903 E-mail: godlewsk@post.queensu.ca
Department of Geography, Queen's University,
Kingston K7L 3N6.

General Research Ethics Board
☐ **Chair: Dr. Joan Stevenson**
E-mail: stevensj@post.queensu.ca
tel. (613)533-6000 ext. 74579
Queen's University, Kingston K7L 3N6

I am aware that my participation is completely voluntary and that I am free to withdraw from the research at any point of time.

I am assured that the researcher shall protect the confidentiality of my identity by not using my name or any other identifying information in the research and keeping the raw data safely in a locked office drawer at Queen's University

Please indicate if you consent to the following by **ticking** either that you **consent** or you **do not** consent to the following practices:

☐ I **consent** to completing two questionnaires
☐ I **do not** consent to completing two questionnaires

☐ I **consent** to the use of participant observation
☐ I **do not** consent to use of participant observation

☐ I **consent** to completing journal entries.
☐ I **do not** consent to completing journal entries

Name: ____________________________________

Date:_____________

Signature: __________________________________

Appendix 2: Participatory Research Evaluation Questionnaire

Participation in the Project

1. Have people within the building been provided with opportunities to participate in the research process?

○ There were no opportunities to participate
○ Participation was not widely promoted
○ More than one approach to promote participation was used
○ Multiple approaches to promote participation were used
○ All obvious approaches to promote participation were used

2. Have efforts been made to overcome barriers to participation (for people with disabilities, seniors etc.)?

○ No efforts to overcome barriers
○ Few efforts made to overcome barriers
○ Reasonable effort made to overcome barriers
○ High level of effort made to overcome barriers
○ All possible efforts to overcome barriers made

3. Was the researcher’s commitment to the project discussed?

○ The researcher’s commitment wasn’t mentioned
○ The researcher’s commitment was mentioned briefly
○ The researcher’s commitment was discussed moderately
○ There was a high level of discussion about the researcher’s commitment
○ The researcher’s commitment was explicitly agreed on

4. What is your understanding of the physical and/or intellectual commitment you and other community members will make to the project?

○	○	○	○	○
The researcher will do everything	The researcher will do everything with some support from the community	About equal efforts by the researcher and the community	Mostly resources and efforts from the community, researcher will have some direct input	The researcher will act as facilitator with the community investing effort and resources

What you will learn...

5. Do you think the project will allow you to make strong connections with others?

○	○	○	○	○
No	Some connections may be made	A moderate number connections may be made	A moderate/high number of connections may be made	A high number of connections are likely to be made

6. Do you think the project will provide you with skills you can use in other parts of your life?

○	○	○	○	○
No	Some valuable skills are likely to be learned	A moderate number of valuable skills are likely to be learned	A moderate/high number of valuable skills are likely to be learned	A high number of valuable skills are likely to be learned

7. Are you and other community members likely to benefit from the research?

○	○	○	○	○
No, only the researcher will benefit	The community benefit will be secondary to the researcher's	The community and researcher are likely to benefit equally	The community will benefit primarily, the researcher secondarily	The benefits to the community have been explicitly agreed upon

8. Did the research topic come from the community?

○	○	○	○	○
No, the researcher posed the topic	The topic mainly came from the researcher with some community input	The researcher and community equally contributed to deciding on the topic	The topic was identified by the researcher with some community input	The topic was posed by the community

Personal Survey Code e.g. lucky number _________

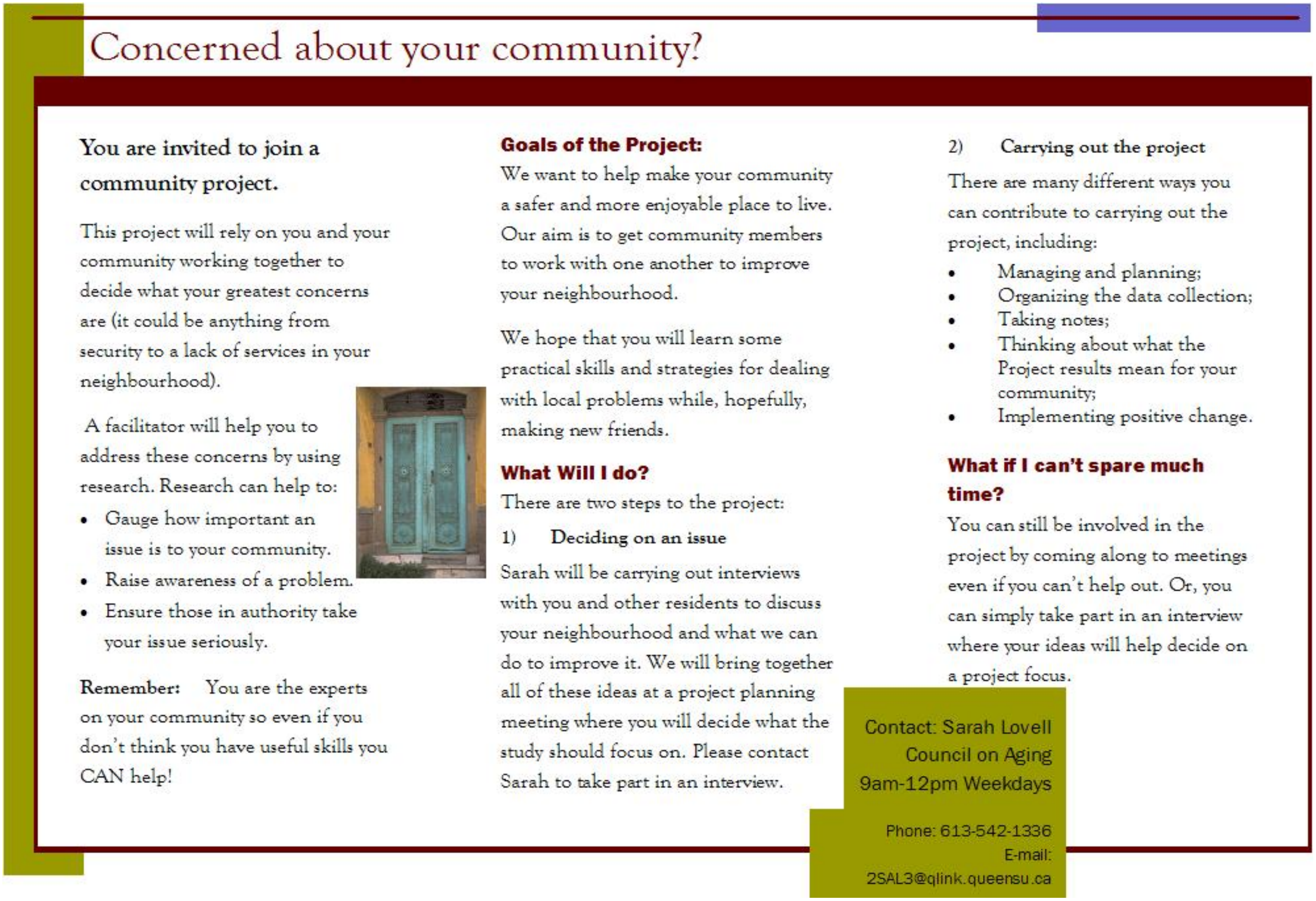
Appendix 3: Participatory Research Questionnaire Results

less participatory → **more participatory**

Q1	2	2		1	2
Q2		1	2		3
Q3			2	1	3
Q4			2	1	3
Q5			2	3	2
Q6		3	2	1	1
Q7			4		3
Q8		2	1		4

See Appendix 2 for detailed questions and options for answering.

Appendix 4: Social Housing CBPR Study Promotion



Concerned about your community?

You are invited to join a community project.

This project will rely on you and your community working together to decide what your greatest concerns are (it could be anything from security to a lack of services in your neighbourhood).

A facilitator will help you to address these concerns by using research. Research can help to:

- Gauge how important an issue is to your community.
- Raise awareness of a problem.
- Ensure those in authority take your issue seriously.

Remember: You are the experts on your community so even if you don't think you have useful skills you CAN help!

Goals of the Project:

We want to help make your community a safer and more enjoyable place to live. Our aim is to get community members to work with one another to improve your neighbourhood.

We hope that you will learn some practical skills and strategies for dealing with local problems while, hopefully, making new friends.

What Will I do?

There are two steps to the project:

1) **Deciding on an issue**

Sarah will be carrying out interviews with you and other residents to discuss your neighbourhood and what we can do to improve it. We will bring together all of these ideas at a project planning meeting where you will decide what the study should focus on. Please contact Sarah to take part in an interview.

2) **Carrying out the project**

There are many different ways you can contribute to carrying out the project, including:

- Managing and planning;
- Organizing the data collection;
- Taking notes;
- Thinking about what the Project results mean for your community;
- Implementing positive change.

What if I can't spare much time?

You can still be involved in the project by coming along to meetings even if you can't help out. Or, you can simply take part in an interview where your ideas will help decide on a project focus.

Contact: Sarah Lovell
Council on Aging
9am-12pm Weekdays

Phone: 613-542-1336
E-mail:
2SAL3@qlink.queensu.ca

Research Proposal:

[Parallel Transit] Bus Study

Background

This study was proposed in response to concerns amongst a group of Parallel Transit Bus users over the flexibility, cost, and availability of Parallel Transit Bus services in the [study city]. The study is participatory involving both representatives from the [Aging organization] and community members who use the [study city] Parallel Transit Bus Services in the design and governance of the study.

The goals of the study are to:

1) Evaluate the experiences of [study city] Parallel Transit Bus Users and the extent to which their needs are being met.
2) Investigate approaches to providing Access Services used in other Ontario cities

Alternative approaches to providing access services will be investigated primarily by reviewing studies completed by the Ontario Ministry of Transportation and other relevant bodies. Discussions with service representatives providing alternative approaches will also inform the final report. These discussions will focus on the costs and benefits of the different approaches.

Methodology

Participant Recruitment

All individuals who have used the [study city] Parallel Transit Bus Services will be eligible to participate in the study. The study will be advertised at health and disability services within the [study city]. Participants will also be recruited using word of mouth amongst the Parallel Transit Bus user community. Persons interested in the study will be asked to phone the [aging organization] and provide details regarding their availability for a meeting.

Study Design

[Study city] Access Services already collect statistics regarding demand for the Parallel Transit Bus based on requests from users. [study city] Access Services acknowledge that demand for their services exceeds supply and limited resources restrict their ability to provide services. Because accurate data of user needs already exists and because there is a poor understanding of the mobility challenges facing people with physical disabilities we are using a qualitative (descriptive) methods within this study. Descriptive accounts of individual experiences using the Parallel Transit Bus services will be solicited from bus users within group discussion settings (focus groups).

Focus groups will be used to evaluate the extent to which the [study city] Parallel Transit Bus service meets the needs of users and the challenges facing users. Focus groups are a way of gauging opinions of the public and prompting discussion on a subject. Approximately 4-6 people will be invited to take part in each focus group and we hope to hold at least four sessions involving a minimum of 20 participants.

The focus groups will be facilitated by an Parallel Transit Bus user trained in group mediation and a note taker will be present at all meetings. The focus group facilitator will be responsible for ensuring the following study questions are addressed and for ensuring that all participants have the opportunity to speak as well as moving the discussion along when no new information is arising.

Focus Group Questions:

1) Please discuss why you began using the Parallel Transit Bus and what other transport options are available to you given your financial situation and your mobility.
2) What financial cost do you face through use of the Parallel Transit Bus in an average week and how does this affect your budget? If you receive ODSP please also explain to what extent your transport costs are covered by the government.
3) Does the flexibility of the bus service impact on your daily activities (e.g. what happens when you have changes in medical appointments, last minute meetings etc.)?
4) Does the efficiency or coordination of the bus routes impact on your use of the Parallel Transit Bus service? Prompts: in terms of timing of buses, collecting multiple passengers etc.
5) What are some of the other strengths and weaknesses of the service you have experienced that we haven't already discussed?

Focus group meetings will last approximately 1-2 hours and will be taped using a digital voice recorder.

Study Results

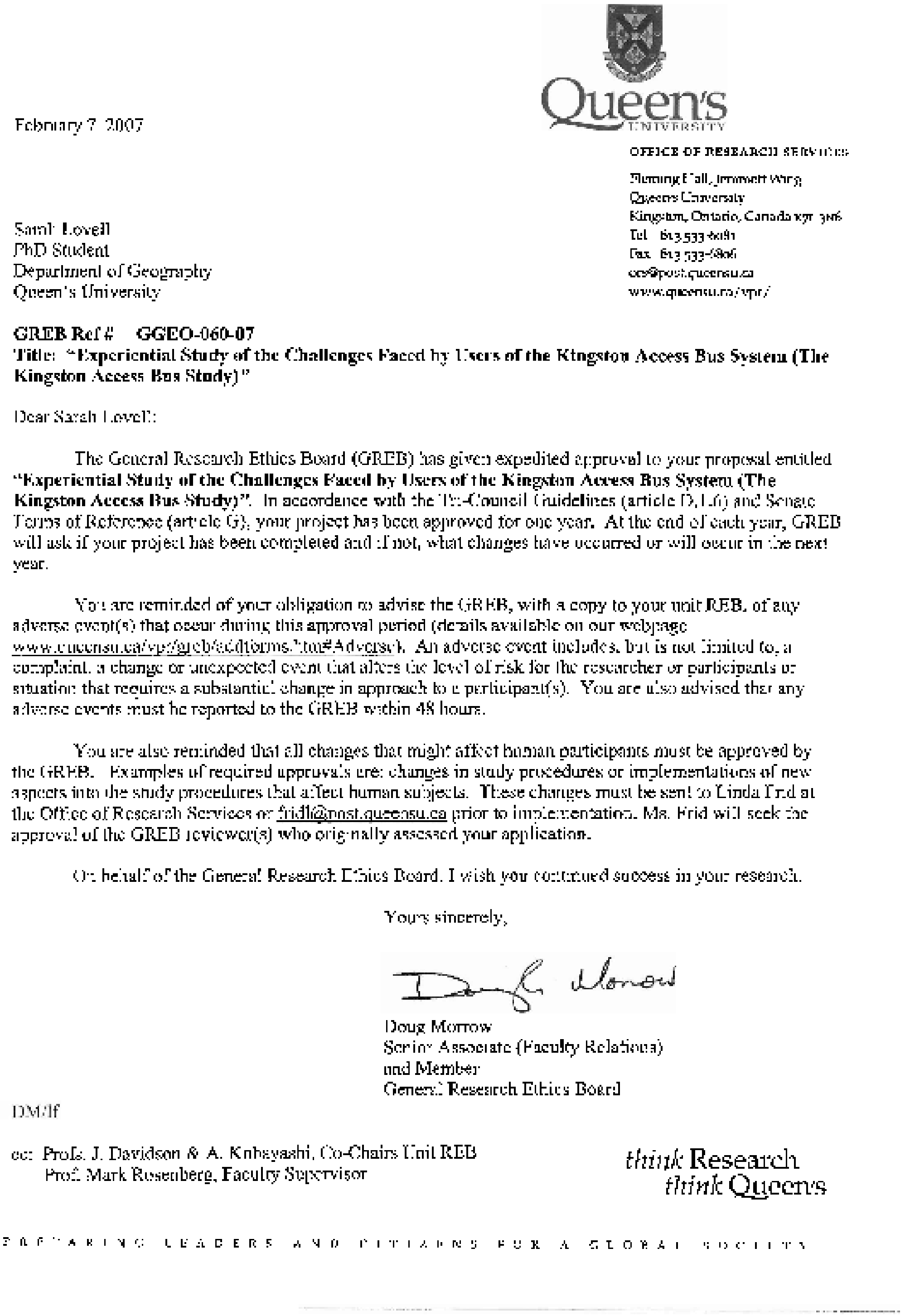
The recordings of the focus groups will be transcribed and analysed using a software programme for qualitative data analysis. The analysis will focus on both exploring the questions identified above and any new themes which emerge over the course of discussions.

The community involved in this study is concerned that present Access services are not meeting the needs of [study city] Parallel Transit Bus users. If the study supports this hypothesis the results will be used to lobby the [study city] Council to commit to an improvement of existing services. The study will also contribute to raising public awareness of the challenges of living with a disability and will inform the academic literature in the areas of critical disability studies and transportation planning through presentations at conferences and published articles. The research results will be distributed to local organizations providing services to people with disability… and local media.

Conclusion

The overriding goal of this study is to evaluate how well the Parallel Transit Bus in [study city] meets the needs of users in terms of flexibility, availability and cost. This will be achieved through a series of focus groups with Parallel Transit Bus users to evaluate their experiences using the service, and through assessments of services in other Ontario cities as a basis for comparison.

Appendix 6: Parallel Transit Study Ethics Approval



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February 7, 2007

Sarah Lovell
PhD Student
Department of Geography
Queen's University

GREB Ref # GGEO-060-07
Title: "Experiential Study of the Challenges Faced by Users of the Kingston Access Bus System (The Kingston Access Bus Study)"

Dear Sarah Lovell:

The General Research Ethics Board (GREB) has given expedited approval to your proposal entitled **"Experiential Study of the Challenges Faced by Users of the Kingston Access Bus System (The Kingston Access Bus Study)"**. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been approved for one year. At the end of each year, GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REB, of any adverse event(s) that occur during this approval period (details available on our webpage www.queensu.ca/vpr/greb/addforms.htm#Adverse). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that any adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be approved by the GREB. Examples of required approvals are: changes in study procedures or implementations of new aspects into the study procedures that affect human subjects. These changes must be sent to Linda Frid at the Office of Research Services or fridl@post.queensu.ca prior to implementation. Ms. Frid will seek the approval of the GREB reviewer(s) who originally assessed your application.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Yours sincerely,

Doug Morrow
Senior Associate (Faculty Relations)
and Member
General Research Ethics Board

DM/lf

cc: Profs. J. Davidson & A. Kobayashi, Co-Chairs Unit REB
Prof. Mark Rosenberg, Faculty Supervisor

think Research
think Queen's

PREPARING LEADERS AND CITIZENS FOR A GLOBAL SOCIETY

Appendix 7: Parallel Transit Study – A Brief Summary of Results

A series of six focus groups were carried out over two months beginning April 12th, 2007 during which 19 bus users, 6 care workers and 1 caregiver took part in discussions. The participants represented a wide cross-section of Parallel Transit Bus Users representing a range of age groups and disabilities and included individuals living in long-term care and affected by brain injuries. The focus groups resulted in 69 pages of transcripts which were analysed in collaboration with the community stakeholders.

The results of the focus groups centered on four key themes. Firstly, with regards to booking buses, participants felt that the customer service staff varied in their willingness and ability to accommodate bus users' needs; the need to provide substantial advance notice in order to be assured of a bus booking negatively impacted on the quality of life of participants restricting their social lives; and the permanent booking system was spoken highly of.

The availability of buses was a second significant theme emerging out of the focus groups and was dominated by concerns over the limited availability of buses on evenings, weekends, and particularly during school-runs.

With respect to using the service, Parallel Transit User's expressed concerns about the limitations of the call-back system particularly during peak usage time. Some participants indicated frustration at the low number of passengers per bus and there was a general consensus that increasing passengers would be an acceptable strategy for making the service more efficient. When riding the Access Bus passengers would benefit from being allowed to take a greater number of groceries on board and having a place to store them.

Finally, Bus User's felt that with greater information they would be better able to navigate the bus system to meet their needs; it was recommended that information be made available for users signing up to the bus system to assist their use of the service.