INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA

UMI
800-521-0600
COMMUNITY PARTNERSHIPS THAT INCLUDE PEOPLE WITH DISABILITIES:

POWER, CULTURE AND VALUES

by

Kari Krogh

A thesis submitted in conformity with the requirements for the Degree of Doctor of Philosophy
Department of Human Development and Applied Psychology
Ontario Institute for Studies in Education of the University of Toronto

© Copyright by Kari Krogh 1998
The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author’s permission.

L’auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L’auteur conserve la propriété du droit d’auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-41452-3
Community Partnerships that Include People with Disabilities:
Power, Culture and Values

Kari S. Krogh
Ph.D.
1998

Department of Human Development and Applied Psychology
Ontario Institute for Studies in Education of the University of Toronto

ABSTRACT
Partnerships have been proposed as an empowering method of addressing a variety of disability-related issues in fields such as health, research, technology design, and policy development. However, people with disabilities remain frustrated by a lack of power sharing. This study examined the involvement of people with disabilities in community partnerships. In particular, the impact of social constructions of disability (medical, charity and independent living) and beliefs regarding knowledge were investigated. Dominant power structures and how they were internalized, accepted or challenged were also examined.

This study incorporated elements of both participatory action research and critical pedagogy. Two groups of multiple stakeholders were observed during their involvement in intensive 4.5 and 3-day workshops designed to explore and facilitate partnership development. Six participants from each of these workshops then engaged in an in-depth, semi-structured interview about their experience and ideas related to disability and partnership. Ten disability leaders involved in community partnerships across Canada were
then brought together over a 4-day period to explore themes derived from the earlier interviews. Through creative methods including story telling, role play, and metaphor analysis, participants verified and elaborated upon these themes and tested their applicability within a variety of settings. These participants were involved in pre and postinterviews and discussions were tape recorded.

People with disabilities reported that they felt their capacities and contributions were often devalued and that their full participation was systematically hampered by commonly held beliefs about expertise, communication and work. The act of representing people with disabilities in a partnership was described as challenging because of the diverse nature of the group and internalized discriminatory practices. Benefits of partnerships and suggestions for supporting them were also documented. Partnerships were found to frequently replicate elements of oppressive relationships and on occasion, foster the development of innovative collaborative relationships. Without challenging the dominant relations of power and beliefs that affect the interactions and outcomes of partnerships, people with disabilities may experience partnerships as oppression. This study suggests a need for all partners to develop a greater awareness of power, accept responsibility for reducing barriers, and work to create new ways of relating.
ACKNOWLEDGEMENTS

I would like to acknowledge the financial assistance of the Social Sciences and Humanities Research Council of Canada in the form of a full Doctoral Fellowship. I would also like to acknowledge the support of my thesis supervisor, Dr. Judith Wiener, and committee members Dr. Budd Hall, Dr. Peter Lindsay, Dr. Esther Geva and Dr. William Boyce.

There are many people with disabilities who have acted as invaluable mentors and peers in the learning and community change efforts that were components of this study. I want in particular to express my appreciation to: Cathy La France of the Cowichan Valley Independent Living Resource Centre; Ronnie Phipps, Paul Gauthier and Joseph Theriault of Beyond Consulting Inc.; Henry CulliHal of the Canadian Centre on Disability Studies; Mary Ennis of the Coalition of Persons with Disabilities for Newfoundland and Labrador; Patricia Flynn of Community Involvement of the Disabled; Sandy MacKinnon of the Prince Edward Island Association for Community Living; Anne Lie Nielson of the Prince Edward Island Council of the Disabled; Patti O'Donnell of New Brunswick - People First; Manuel Salinas of the Hispanic Community Centre Society of British Columbia; and Marilyn Warf of Persons United for Self-Help of Northwestern Ontario, as well as Linda St. Maurice and Dr. Patricia Pardo. My hope is that each contributor gained something useful from their participation.
I would also like to thank the many other people who supported me in my work on the thesis through their participation, intellectual guidance, moral support or editorial assistance. Among others, these people include: Lew Boles, Megan Terepocki, Harold White and Denise Coulbeck.

Finally, I would like to express my deepest appreciation for the incredible support that I received from my best friend and partner, David Gordon.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>iv</td>
</tr>
<tr>
<td>List of Figures</td>
<td>xi</td>
</tr>
<tr>
<td><strong>Chapter 1: Introduction</strong></td>
<td>1</td>
</tr>
<tr>
<td>Overview</td>
<td>1</td>
</tr>
<tr>
<td>Terminology</td>
<td>2</td>
</tr>
<tr>
<td>Impairment, Disability and Handicap</td>
<td>3</td>
</tr>
<tr>
<td>Community of People with Disabilities</td>
<td>3</td>
</tr>
<tr>
<td>Consumer</td>
<td>3</td>
</tr>
<tr>
<td>Insider and Outsider</td>
<td>4</td>
</tr>
<tr>
<td>Cross-disability and Uni-disability</td>
<td>4</td>
</tr>
<tr>
<td>Consumer-directed</td>
<td>5</td>
</tr>
<tr>
<td>Service Provider</td>
<td>5</td>
</tr>
<tr>
<td>Partnerships</td>
<td>6</td>
</tr>
<tr>
<td>Collaborative Community Partnership</td>
<td>6</td>
</tr>
<tr>
<td>Research Partnerships</td>
<td>6</td>
</tr>
<tr>
<td>Inclusion versus Meaningful Participation</td>
<td>7</td>
</tr>
<tr>
<td>Sociopolitical Context</td>
<td>7</td>
</tr>
<tr>
<td>Government Programs and Policy</td>
<td>8</td>
</tr>
<tr>
<td>Disability Organization Programs and Policy</td>
<td>10</td>
</tr>
<tr>
<td>Partnership Agreements Within Different Settings</td>
<td>14</td>
</tr>
<tr>
<td>Locating Myself and My Learning Experiences</td>
<td>15</td>
</tr>
<tr>
<td>Personal Experience with Disability</td>
<td>15</td>
</tr>
<tr>
<td>Most Influential Partnership Experience</td>
<td>17</td>
</tr>
<tr>
<td>Rationale for Studying Partnerships</td>
<td>18</td>
</tr>
<tr>
<td>Defining the Research Questions Guiding the Investigation</td>
<td>20</td>
</tr>
<tr>
<td><strong>Chapter 2: Review of the Literature</strong></td>
<td>21</td>
</tr>
<tr>
<td>Introduction</td>
<td>21</td>
</tr>
<tr>
<td>Situation of People with Disabilities in Canada</td>
<td>22</td>
</tr>
<tr>
<td>Models of Disability</td>
<td>24</td>
</tr>
<tr>
<td>Medical and Charity Models of Disability Support</td>
<td>24</td>
</tr>
<tr>
<td>Newer Models of Disability Support: Independent Living Models</td>
<td>25</td>
</tr>
<tr>
<td>Health Promotion</td>
<td>26</td>
</tr>
<tr>
<td>Present Context of Partnerships in Canada</td>
<td>27</td>
</tr>
<tr>
<td>Challenges of Partnership</td>
<td>29</td>
</tr>
<tr>
<td>Theories of Power and Subordination</td>
<td>30</td>
</tr>
<tr>
<td>Research on Methodologies for Investigating Disability</td>
<td>39</td>
</tr>
<tr>
<td>Research Questions</td>
<td>44</td>
</tr>
</tbody>
</table>
**Chapter 3: Method**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>45</td>
</tr>
<tr>
<td>Research Site, Data Collection and Negotiating Terms of Participation</td>
<td>45</td>
</tr>
<tr>
<td>Identifying a Study Site and Community Research Partner</td>
<td>47</td>
</tr>
<tr>
<td>Negotiating Terms of Participation and Ethical Issues</td>
<td>49</td>
</tr>
<tr>
<td>Research Phases</td>
<td>51</td>
</tr>
<tr>
<td>Phase One</td>
<td>51</td>
</tr>
<tr>
<td>Phase Two</td>
<td>54</td>
</tr>
<tr>
<td>Phase Three</td>
<td>58</td>
</tr>
<tr>
<td>Researcher Roles</td>
<td>65</td>
</tr>
<tr>
<td>Multiple Roles</td>
<td>65</td>
</tr>
<tr>
<td>Anticipated Benefits and Drawbacks of Consumer-Researcher Location</td>
<td>66</td>
</tr>
<tr>
<td>Previous Work On Partnership: Community, Academic and Service Sectors</td>
<td>67</td>
</tr>
<tr>
<td>Data Collection and Analysis</td>
<td>69</td>
</tr>
<tr>
<td>Interview Approach</td>
<td>69</td>
</tr>
<tr>
<td>Thesis Journal</td>
<td>71</td>
</tr>
<tr>
<td>Addressing Bias in Research</td>
<td>71</td>
</tr>
<tr>
<td>Cycles of Data Collection, Analysis, and Action</td>
<td>72</td>
</tr>
<tr>
<td>Composite Data Analysis</td>
<td>73</td>
</tr>
<tr>
<td>Applying Research Quality and Emancipation Criteria</td>
<td>74</td>
</tr>
<tr>
<td>Credibility</td>
<td>74</td>
</tr>
<tr>
<td>Transferability</td>
<td>77</td>
</tr>
<tr>
<td>Dependability</td>
<td>77</td>
</tr>
<tr>
<td>Confirmability</td>
<td>77</td>
</tr>
<tr>
<td>Authenticity</td>
<td>78</td>
</tr>
<tr>
<td>Conscientization</td>
<td>78</td>
</tr>
<tr>
<td>Catalytic Validity</td>
<td>79</td>
</tr>
<tr>
<td>Standpoint Epistemology</td>
<td>80</td>
</tr>
<tr>
<td>Reciprocity</td>
<td>80</td>
</tr>
<tr>
<td>Sharing the Perquisites of Privilege</td>
<td>81</td>
</tr>
<tr>
<td>Summary</td>
<td>81</td>
</tr>
</tbody>
</table>

**Chapter 4: Attitudes and Values that Affect Participation in Partnerships**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>82</td>
</tr>
<tr>
<td>Attitudes Toward People with Disabilities: Medical and Charity Models of Support</td>
<td>82</td>
</tr>
<tr>
<td>A Focus on Disability Rather than Ability</td>
<td>83</td>
</tr>
<tr>
<td>Expected Disabled and Caregiver Roles</td>
<td>84</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Attitudes of People with Disabilities toward Themselves</td>
<td></td>
</tr>
<tr>
<td>and Others: Recognizing Capacity and Heterogeneity</td>
<td>88</td>
</tr>
<tr>
<td>Emphasis that People with Disabilities Place on their</td>
<td></td>
</tr>
<tr>
<td>Capabilities</td>
<td>88</td>
</tr>
<tr>
<td>Heterogeneity within the Disability Community</td>
<td>89</td>
</tr>
<tr>
<td>Attitudes of People with Disabilities toward Others</td>
<td>90</td>
</tr>
<tr>
<td>Value Conflicts Affecting Partnerships</td>
<td>91</td>
</tr>
<tr>
<td>The Role of Emotion in Communication</td>
<td>91</td>
</tr>
<tr>
<td>Perspectives about Time</td>
<td>94</td>
</tr>
<tr>
<td>Appreciating Different Forms of Contribution</td>
<td>97</td>
</tr>
<tr>
<td>Heterogeneity within the Disability Community</td>
<td></td>
</tr>
<tr>
<td>Tokenism and Consumer Control</td>
<td>100</td>
</tr>
<tr>
<td>Images of Tokenism</td>
<td>100</td>
</tr>
<tr>
<td>Consumer Control in Partnerships</td>
<td>103</td>
</tr>
<tr>
<td>Barriers to Successful Partnership Relationships</td>
<td>106</td>
</tr>
<tr>
<td>Ability to Relate to One Another</td>
<td>107</td>
</tr>
<tr>
<td>Power Positions Reinforced</td>
<td>107</td>
</tr>
<tr>
<td>Personal and Political Resistance</td>
<td>110</td>
</tr>
<tr>
<td>Meaningful Participation in Partnerships</td>
<td>113</td>
</tr>
<tr>
<td>Challenge of Personal Change</td>
<td>113</td>
</tr>
<tr>
<td>Clarifying Level of Involvement in Partnerships</td>
<td>116</td>
</tr>
<tr>
<td>Contextual Factors Affecting the Partnership</td>
<td>117</td>
</tr>
<tr>
<td>Summary</td>
<td>120</td>
</tr>
</tbody>
</table>

**Chapter 5: Representation Issues**                        121

**Introduction**                                             121

**Representation Issues within Community Partnerships**      122

People with Disabilities Not Initially

Considered Legitimate Partners                                 122

Influence of Recruitment Methods                               123

Impact of Partnership Operating Structure on Equity           124

Specific Representation Issues within

the Disability Community                                      129

Disability, Gender and Cultural Discrimination                129

Power Struggles within Disability Community                  132

The Need for Representatives who Speak Out                   135

Support for Representatives                                  136

**Sharing Power**                                            140

Recognizing One's Own Power                                   140

Redistributing Power                                         142

Flexibility in the Ways People See Themselves

and Others                                                  144
Chapter 7: Discussion and Conclusions

Personal Reflections about Methodology................................. 215
Employing Critical Pedagogy.................................................. 215
Making Research Useful...................................................... 217
Multiple Positions and Roles: Consumer Researcher............... 218
Partnership as a Process..................................................... 220
The Role of Beliefs and Values in Partnerships.......................... 224
Social Construction of Disability........................................... 224
The Work Process within Partnerships.................................... 228
Role of Emotion and Creativity in Articulating
Lived Experience..................................................................... 231
Representing Disability.......................................................... 235
Diversity of Perspective among People with Disabilities............ 235
The Oppressed as Oppressor.................................................. 239
Power in Partnership............................................................. 243
Consenting to Existing Power Relations................................. 243
Challenging Power Relations through Consumer
Control.................................................................................. 247
Limitations............................................................................. 251
Conclusions: Creating New Ways of Relating.......................... 253
Final Remarks......................................................................... 255

References............................................................................. 256

Appendices............................................................................. 264
Appendix A: Partnership Agreement Framework...................... 264
Appendix B: Sample Partnership Agreement............................ 266
Appendix C: Sample Informed Consent Form............................ 270
Appendix D: Sample Administrative Consent............................ 273
Appendix E: Sample Questions Guide...................................... 274
Appendix F: Participant Descriptions from the Third Workshop... 277
List of Figures

Figure 1: Process of collaborative community partnerships............ 221
CHAPTER 1
INTRODUCTION

Overview

Collaborative community partnerships (CCP) have been proposed as an approach to addressing issues affecting people with disabilities. It is frequently assumed that the partnership process fosters empowerment. In this thesis I examine the experiences of people with disabilities in a variety of CCPs. In particular, issues related to the impact of power, culture and values are examined as people with disabilities work together with members of other stakeholder groups such as community groups, service providers, government and academic researchers, to achieve a goal that is considered of mutual interest. With a view to designing better CCPs, I particularly wanted to learn of experiences and contexts which people with disabilities found most favorable to their empowerment, self-worth and independence.

The methodological approach of this thesis combines participatory action research and critical pedagogy (Freire, 1993; Hall, 1975). When I began this study I prepared a broad conceptual framework of elements of partnership that I thought were important based on my previous direct experience with partnerships that included people with disabilities and relevant literature. I used this as a guide for establishing a relationship with a disability organization that acted as a partner in the research. The study and the research relationship provided opportunities for rethinking
and further developing my ideas of partnership based on careful documentation of the ideas and experiences of others.

This study involved gathering data from two partnership workshop projects organized by a disability organization. In the third phase, broader application of the theory derived from this data was tested when disability leaders from across Canada were brought together to participate in a four-day workshop. These participants were involved in representing people with disabilities in collaborative community partnerships. During this workshop, participants were guided through activities that were specifically designed to facilitate an examination of partnership issues. During this process the relevance and applicability of the themes derived from the previous two phases of the research were tested.

In this chapter the phenomenon of collaborative community partnerships that include people with disabilities is described and placed within a sociopolitical context in Canada. I also describe my personal experiences with disability and disability organizations. In the discussion I outline activities that led to the development of my interest in partnerships and conclude by stating and defining the central research question of the study.

**Terminology**

I will repeatedly make reference to the following terms that represent essential concepts within the study. These terms should not be considered definitive, rather they are presented for the purpose of introducing the reader to the main ideas within the thesis as I conceptualise them.
**Impairment, Disability and Handicap**

An *impairment* refers to an abnormal function within the body at a cellular or molecular level. A *disability* on the other hand, exists when a person is required to use alternative means to achieve their goals as a result of an impairment. *Handicaps* are created when a person with a disability is in a restrictive environment that does not allow the achievement of a desired goal (World Health Organization, 1980).

**Community of People with Disabilities**

The term *community of people with disabilities* is used within this thesis to refer to a group of people who have their lived experience with disability in common and who have come to work together to address common concerns. The experience of living with a disability can vary greatly depending on a number of factors such as the type and severity of disability, whether it is acquired or congenital, and a myriad of personal characteristics including personality, socioeconomic status, cultural background and level of comfort with disability. Not all people who live with an impairment consider themselves disabled or if they do they may choose not to be active in the community of people working to address disability issues. Due to the challenges in defining this group, some people question the use of the term "community" as it is applied to this group of people (C. Lysack, personal communication, June, 1997).

**Consumer**

This is a term that is frequently used to refer to a person with a disability. The term originated from the development of Independent Living
theory. Its use is intended to place persons with disabilities who typically require some form of special service in a position of power with respect to those who provide or fund services.

**Insider and Outsider**

These terms are used frequently within qualitative research to describe the location of the researcher with regard to their membership status within the group that is being studied (Ng & Ramirez, 1981; Standfield, 1994). A person who is an *insider* is assumed to have insights into the experience and culture of people who live as members of the group. It is thought, for example that people who have lived with a disability share the experience of challenging stereotypes and therefore share a common knowledge on this topic. Outsiders are thought to not share *common* experiences that form a basis for understanding the world of group members. These terms are frequently used in research discussions about the methods used to access information from within a perceived community (Lincoln & Guba, 1985) and also to situate the researcher (e.g., Ristock & Pennell, 1996).

**Cross-disability and Uni-disability**

An organization or group composed of and interested in the needs of people with many types of disabilities is described as a *cross-disability* organization. In contrast, a *uni-disability* group serves people with one type of disability such as multiple sclerosis. Cross-disability groups often work on issues such as housing, health care services and employment as they affect people regardless of their disability type.
**Consumer-directed**

In the present context, *consumer-directed* refers to an organization or initiative that is considered to be strongly influenced if not controlled by people who have had the experience of living with disability. With respect to organizations, the term is used to refer to those that are composed "of" people with disabilities to support their empowerment and choices in independent living. These organizations are distinct from others that are considered to be "for" people with disabilities. The latter type of organization is usually directed by nondisabled people who are frequently influenced by a charity or medical model of disability. Those who use a consumer-directed approach recognize expertise based on lived experience and the right of people with disabilities to make decisions that affect their lives even if it involves risk. Self-help and peer-support are approaches that are consistent with a consumer-directed model. Consumer-directed organizations support self-governance by having a board of directors and staff that are primarily composed of people with disabilities.

**Service Provider**

A *service provider* refers to persons typically linked to an institution and professional association, who provide services to people with disabilities. Service providers would include, for example, occupational therapists, special educators and social workers. Their work has traditionally been associated with medical or charity models of disability. Some people with disabilities have sought to operate consumer-directed initiatives or to negotiate community partnerships as a way to redistribute the resources and alter the approach taken by service providers.
Partnerships

A clear definition of partnership is essential since different interpretations may lead to misunderstandings about the work and working relationships involved. The Conference Board of Canada has developed the following definition:

a relationship involving two or more organizations that have agreed to work co-operatively with the common goal of addressing human/community issues or set of issues. A partnership requires the sharing of power, work, support, and information with others. Through mutual agreement and shared values, a partnership confers benefits on each partner as well as the community while fostering an achievement of ends that are acceptable to all participants. (Audet & Rostami, 1993, p. 3)

Collaborative Community Partnership

The term Collaborative Community Partnership (CCP) is used in the present project to describe those partnerships that involve the community sector with any other sector or sectors such as health, government, law or business. This term also further defines the type of partnership in relation to the extent of shared decision making. CCPs implicitly or explicitly imply or propose the sharing of power among its partner members. Although a CCP may include a variety of sectors, in one way or another they include representation from the community either through a nonprofit community group or individuals.

Research Partnerships

Research partnerships, within this study, are a type of CCP. This partnership includes both the interests of community members, through formal representation from a nonprofit community group and researchers
who may be affiliated with an academic, health care or private research institution. It is collaborative in that the partners work together to meet both community and research goals within a relationship that attempts to share decision making on at least some aspects of the investigation.

**Inclusion versus Meaningful Participation**

There is a critical difference that has been recognized by people with disabilities between their inclusion and their meaningful participation in partnerships. People with disabilities may be included in partnerships in which dominant stakeholders choose to reduce or ignore their input. To actually involve people with disabilities in a meaningful way, some level of control is considered important (see p. 6, definition of partnership). For participation to be considered anything beyond tokenism and manipulation, three preconditions must be met according to Drake (1992): “a) that consumers must have the capacity of actually exercising power; b) that consumers must occupy roles in which power can be exercised; they must have authority; and c) that the role must be situated within networks such that the exercise of power is effective: that it achieves its purpose” (p. 271).

**Sociopolitical Context**

This study of community partnerships that include people with disabilities arose from a particular sociopolitical context characterised by government policy, organizational programs and individual perceptions.
Government Programs and Policy

Human Resources Development Canada has introduced several funding programs during the past decade that have significantly influenced efforts to create community partnerships that include people with disabilities. From 1992 to 1995, a program called the Disabled Person Participation Program (DPPP) allocated funds to support projects that aimed to include people with disabilities in multisector initiatives.

The nature of the projects that were funded varied greatly. This special funding program allowed for, in some cases, innovations in collaborative methodology to develop with applications in many sectors. Three examples of projects in which I have been involved are: a) funding to a consumer-research collaboration committee to hold symposia and workshops to explore issues related to equity in research partnerships that include people with disabilities and how such partnerships might be used to facilitate social change; b) funding to a research team to create a video produced by a team of researchers, engineers, and assistive technology users that presents the importance of involving people with disabilities in the design of the assistive technologies that they use in everyday living; and c) funding to bring together academic researchers, clinical researchers and persons with disabilities to establish guidelines for collaborative research to be applied within a rehabilitation centre. Since researchers, service providers and disability organizations could apply for these funds, I was able to explore community partnerships from many vantage points that addressed diverse issues and environments for applications.
The Social and Employability Partnership Program (SEPP) was a new federal government program introduced in 1995. This funding program had a much more limited mandate to support partnerships that were specifically targeted to support people with disabilities in obtaining employment or related skills. The replacement of the DPPP program with the SEPP coincided with the Liberal Government's movement during 1996 to reduce general funding for community-based disability organizations and their broader community initiatives.

Another significant funding program that influenced partnerships in disability research was established in 1994. The Social Sciences and Humanities Research Council of Canada in collaboration with the Status of Disabled Persons Secretariat (Human Resources Development Canada) established a four-year, $1.5 million fund to support academic research in the area of social and economic integration of people with disabilities (Social Sciences and Humanities Research Council, 1993). What made this program unique was its directive to support the exploration of ways to involve disability organizations in university-based research. As someone who both served on the review committee for two years and who later received a grant, I found that this program provided unique opportunities for researchers to implement a variety of research methodologies that included representation from the community of people with disabilities.

While this program gave legitimacy to inclusive research practices, the traditional structures of research production remained to a large degree unchanged, allowing for somewhat limited systemic modifications to take place. For example, although people with disabilities were encouraged to have a say in the research direction, they were not to play a role in
administering the funds, thereby reducing their position of influence from which to participate. What these funds did permit, however, was the direct exploration of the dilemmas that occur in collaborative research, such as issues of controlling the research direction, ownership of results, and co-authorship, for those researchers who decided to involve people with disabilities. In several ways, this fund supported a relatively small number of researchers across Canada in using a variety of collaborative research approaches that were intended to be not only academically rigorous but also of relevance to community members with disabilities.

As a result of the funding and acknowledgement provided by these government programs, sectors of society such as academic researchers, health care service providers, and program administrators approached disability organizations to form partnerships. One of the motivations for issuing this invitation was clearly to meet a requirement for receiving government funding. This led to several types of responses from individuals with disabilities and disability organizations ranging from enthusiastic agreement to participate with the hope of equity to outright rejection of almost any proposal to collaborate based on disappointing past experiences.

**Disability Organization Programs and Policy**

In Canada, disability organizations have been divided into Advocacy Groups and Independent Living Resource Centres. Some groups such as the Council for Canadians with Disabilities support people with disabilities on a collective, political advocacy level by lobbying governments directly and fighting cases in court to establish precedents. Most of my direct involvement in disability organizations has been with Independent Living
organizations. The Independent Living Resource Centres have a mandate to provide peer support, as well as information and referral services to people who have any form of disability. These organizations are also involved, to varying degrees, in advocacy but only on a one-to-one basis. These centres are consumer-directed.

Several advocacy organizations have worked on developing partnerships. People United for Self Help of Northwestern Ontario, for example, is one cross-disability, consumer-directed advocacy group that has become very involved in developing partnerships. One of their partnerships is with the municipality of Thunder Bay to review blueprints of all new buildings by a panel of persons with disabilities to ensure that they would be accessible. This partnership developed over time to include other elements such as disability awareness and training among municipal employees. Some advocacy groups remained suspicious of the motivations underlying requests for partnering. For example, the British Columbia Coalition for People with Disabilities, one of the largest advocacy groups in Canada, imposed limits on the extent to which they would partner with government, insisting that they receive less than half of their funding from government sources in order to remain in a position to meet their goal of lobbying the government on disability issues.

Some disability organizations, such as the Centre for Independent Living in Toronto (CILT), where I acted as a board member from 1990 to 1996, became suspicious of the many letters requesting our organization's involvement in a "partnership" that would link us with, for example, rehabilitation centres, academic institutions or service organizations. We became concerned because through experience we discovered that the
influence we had was limited; we were asked to participate on someone else's terms. The nature of our participation frequently appeared to be defined by the partner who, from the beginning, also held the position of power to control project initiation, communication, budgeting, administration and management. Organizations such as CILT found research partnerships to be particularly problematic. Several members of CILT were also interested in finding ways of doing research that would not place people in the position of object (Oliver, 1992). As Woodill et al. (1992) explain, there has been a long history of objectification of people with disabilities, particularly within medical research.

In response to these concerns, CILT initiated a project to examine which research methods were most compatible with the Independent Living Philosophy. As a result, a book entitled *Independent Living and Participation in Research: A Critical Review* (Woodill et al., 1992) was written and published. (Participatory Action Research was found to be one of the most appropriate approaches.) Interest in these issues also existed at the national level. As a member of the Canadian Association for Independent Living Centres' Research Committee during 1994 and 1995, I was involved in developing a guidebook for their 21 member organizations on the participation of people with disabilities in research. This guidebook used plain language to describe many of the concerns identified by people with disabilities. It also included a list of questions that representatives from Independent Living Centres could put to researchers or service providers proposing a research partnership. The questions probed issues related to the researcher, the methodological approach used, the identification of the
topic being studied, the framing of the research question and the collaborative research relationship.

Several of the Independent Living Resource Centres (ILRC) were approaching partnerships, particularly research partnerships, with caution between 1993-1995. However, I observed other disability representatives who quickly entered into partnerships with high expectations in terms of both the collaborative relationship and achieving the collective goal.

By 1996 I had observed more hesitation on the part of ILRCs about partnership. In my role as research coordinator for a national study on strategies to support the operation of disability organizations in the changing sociopolitical contexts (Boyce, Krogh, La France, Kaufert, Enns, & Hall, 1996), I consulted with approximately 25 disability organizations about various strategies including community partnerships that could be used to achieve their goals. Several representatives of these organizations expressed concerns, reluctance or reduced expectations regarding CCPs based on negative experiences. In fact, one group of participants chose to discuss what they called “forced partnerships”; those that were driven by government programs' funding policy or suspected implicit government agendas. A drawback identified in a research workshop for this project on organizational strategies was having the strong philosophical positions of a community group coopted by either the value systems of the other sectors or by the mandates of more powerful partner groups (Krogh, Boyce, La France, Enns, Kaufert, & Hall, 1998).

Partnerships, however, remain a popular approach. Given the economic reality of disability organizations today, partnerships are considered by many to be an effective way to function with reduced
resources. Some organizations attempting to cope with federal government funding cuts are feeling pressured to explore all options before shutting down their organization. Several have taken the approach of negotiating and monitoring the partnership relationship as a guarded way to employ this strategy. To support the negotiation process, the Partnership Agreement Framework (Krogh, 1994, 1996) has been used by some disability organizations such as the Canadian Association of Independent Living Centres, Cowichan Valley Independent Living Resource Centre, Vernon Independent Living Resource Centre (L. St. Maurice, C. La France, B. Bryan, personal communication, August 11, 1995). Within this approach members of the partnership are encouraged to discuss essential pieces of the relationship in terms of specific arrangements.

It should be noted that other researchers have also been developing frameworks for understanding relationships between people with disabilities and others within collaborative relationships (Lord, 1994; J. Pivik, personal communication, 1997). The growing interest in applying a partnership approach to addressing disability issues is demonstrated by the special issue of the Canadian Journal of Rehabilitation on this topic (Krogh, in press).

**Partnership Agreements Within Different Settings**

The issue of negotiating a partnership is not the exclusive concern of people with disabilities. An interest in addressing issues related to the power, control, processes and outcomes of collaborative work is shared by many groups that have also experienced a history of oppression in one form or another. For example, Inuit groups have used a framework in negotiating their relationships with researchers and service providers who come from
outside their community to study their population. The Royal Commission on Aboriginal Affairs makes reference to this issue as well. In addition, unions have also been involved in deconstructing participation programs such as partnerships that are used strategically by management in the workplace (Parker & Slaughter, 1994). Women's Centres have also been involved in using the Partnership Agreement Framework (Krogh, 1996) to negotiate their working relationships with others (O. Landry, personal communication, September 20, 1995).

**Locating Myself and My Learning Experiences**

**Personal Experience with Disability**

My efforts to locate myself in my research originate from a desire to facilitate the reader's understanding of the perspective from which I work and write. I acknowledge that not only have I influenced the research but that it has affected me. These are issues that have been discussed extensively by others (Fine, 1994; Giroux, 1992; Van Maanen, 1988).

I have quite a unique relationship with the community of people with disabilities, the group that is under investigation in this study. My voice is one that spans both the "insider" and "outsider" positions. Although I was born a white, able-bodied, middle-class girl, I acquired a disability as a young adult that affected my everyday living. This transition was not only a struggle for me but also for those around me who were confused by the lack of visible signs of difference, as well as by the fluctuation in my ability to function physically. The characteristics of invisible and fluctuating impairment are not consistent with commonly held perceptions of disability (Hannaford, 1985).
One of my greatest challenges was finding congruence between the way I saw myself and the way others saw me, something I suspect that many people with disabilities experience to various degrees. I searched for a place of belonging; a place where I could share my new identity with others and address common issues. At times, I did not fit within the "able-bodied" world and yet soon after acquiring my disability, I met with some resistance or prejudice from a few members of the "disability community." They found it difficult to accept a broader definition of disability that could include people with invisible disability and adhered to a hierarchy of disability.

Approximately half way through my doctoral degree, I once again made a shift across the ability-disability identity border. This came as a result of a stable improvement in my health, something that I believe approximately one third of those with the same condition experience. This identity transition was complicated by the fact that my political identification remained closely connected to disability rights. As I rejoiced in an unanticipated recovery, I once again grieved the loss of an identity. At this time I was concerned about losing not only community membership but also a connection to a political struggle that had become integral to my ways of thinking and being. With time, I came to recognize that the experience of disability will always be a part of me and that I will remain connected to the disability community in some way regardless of the physical state of my body.

My unique position as both an academic and a community member has also influenced the way that I have experienced, explored and studied the topics of CCPs. I have experience being in the positions of consumer, disability organization representative, academic researcher and service
provider. I speak as a woman who has experienced discrimination based on age, gender, disability, disability-type and ability. I do not presume to have the authentic voice of people with disabilities, as I do not believe that there is a single, homogeneous perspective to portray. I have a unique perspective, as each author, ethnographer, and researcher does. I have attempted to make my position transparent so that a reader can take it into consideration in assessing the present account of my research.

**Most Influential Partnership Experience**

I worked for two years as a consumer-researcher collaboration coordinator to promote the meaningful participation of people with disabilities in a very challenging multiuniversity partnership. In terms of my understanding of partnerships that include people with disabilities, this was the most significant learning experience for me prior to beginning my doctoral dissertation. It is also what gave me the desire to spend a great deal of energy to understand partnerships better through doctoral research.

There were significant systemic, attitudinal and physical barriers within this partnership. As a result of the difficulties that these barriers caused, the development of collaborative working relationships appeared to me to progress slowly and at times regress. After significant efforts to bring together very diverse partners, I came to the conclusion that by continuing to participate in the project I would be contributing to the oppression of people with disabilities instead of to the goal of collaboration. While some people with disabilities withdrew from the partnership project at the same time as I did, others decided to remain. The significance of different interpretations of experience is reflected in the central research question.
This was a critical point in my thinking about partnerships that include people with disabilities. As I questioned the use of the term partnership to describe this relationship, I came to recognize the importance of attempting to develop a common vision of partnership among all of the people involved.

When I left this "partnership," I reflected on what could have been done differently to avoid or reduce the complications we experienced. In particular, I felt that people with disabilities needed additional support to negotiate the terms of their participation in partnerships, especially since the political climate was such that projects were receiving funding on the auspices that a "partnership approach" was being used. I also felt that those individuals from other stakeholder groups who sincerely wanted to build more equitable partnerships needed some assistance to do so. At this time I developed the first draft of the Partnership Agreement Framework (see Appendix A). This was published both in a community document (Krogh & Petric, 1994) and later, after it was refined, in an academic journal (Krogh, 1996). This was done in an effort to support change from both locations: community and academia. The Partnership Agreement Framework represents my evolving conceptual understanding of partnerships. This thesis study was intended to lead to a further refinement of this framework through the systematic collection and analysis of data from a variety of sources.

**Rationale for Studying Partnerships**

People with disabilities and disability organization representatives are increasingly being asked to participate in CCPs. In some situations, a funder will require that a partnership approach is taken. Many people with
disabilities, however, have become quite suspicious or reluctant to participate in such partnerships because they feel serious issues related to power are not addressed (M. Salinas, personal communication, August, 1995). Initial experiences in using collaborative methods to address a community concern have left many of the partners with a greater awareness of the challenges involved. Some researchers may become frustrated with the amount of time required to invest in the relationship and process as opposed to achieving measurable targeted outcomes (W. Boyce, personal communication, October, 1993). Yet without some attention to these areas, people with disabilities may be reluctant to continue participating. In order for all partners to experience more satisfaction from such relationships there is a need to understand the complex issues involved, as well as the ways that they may be addressed (Lord, 1994).

Research has shown that involving relevant partners in community initiatives leads to greater success with outcomes (Giesbretch & Feris, 1993). It has also been argued that collaborative approaches that challenge the status quo of research (knowledge) production can be emancipatory for those who typically experience less power in society (Oliver, 1992). Some argue that the use of these types of methods are worthy in that they attempt to shift these power relations (Drake, 1992). Regardless of the source of the interest, one cannot disregard the difficulties involved in negotiating a community partnership that brings together people who in some respects belong to different cultures who use their own jargon and share experiences within their particular partner group. In this thesis I explore the complex nature of collaborative community partnerships.
Defining the Research Questions Guiding the Investigation

Previous ideas arising from experience led me to identify the central research question as, "How do people with disabilities experience and understand their involvement in collaborative community partnerships?" In this initial guiding question, the component elements must be carefully defined. The question explores initiatives involving members of different sectors including the community in achieving a goal that is of mutual interest. The initiative explicitly or implicitly attempts to include people with disabilities in a collaborative manner; however, the extent to which they are actually involved in sharing power may vary. The intention was to use this broad question in conjunction with the investigative approach described in Chapter 3, that would allow other relevant themes to emerge from the data gathered.
CHAPTER 2
REVIEW OF THE LITERATURE

Introduction

In this chapter, I describe the present social, political and economic conditions in which people with disabilities live; positions that are typically characterized by poverty and a lack of power. Ways of conceiving disability – the Medical, Charity, and Independent Living Models of support – are then presented. Health promotion is also discussed as an approach that aims to empower those who receive services. I explain how the lens through which disability is viewed significantly affects the life experiences of people with disabilities. Contextual factors are reviewed including service providers' interest in approaches that are empowering and the government's encouragement of a partnership approach to address a range of issues. The challenges of partnerships that have been identified in the limited available research are also discussed.

Major theories and concepts related to power are discussed. Lukes (1974), who summarizes various models, concludes that a model of power must include behaviors and effects that are not easily observable. Bourdieu and Passeron's (1977) theory of oppression presents power as something that is often unrecognized and that is reproduced or reinforced through threat of rejection, common-sense thinking and self-censorship. Raising critical awareness of power structures among those who are oppressed is
also reviewed (Freire, 1993). Several feminists, who draw on the examination of difference within a dominant power system, make relevant contributions to the present investigation. Central concepts described by academics and theorists who have disabilities are also reviewed, including the concepts of othering and social construction of disability (Oliver, 1990; Wendell, 1996). The work of several researchers such as Hall (1975), Freire (1993), Lather (1986b) and Oliver (1992) is discussed in relation to its influence on the design of this study. The chapter concludes with a set of specific questions to guide the investigation.

**Situation of People with Disabilities in Canada**

According to Statistics Canada, 17.8% of the adult population or a total of 4.2 million people in Canada had disabilities in 1991 (Fawcett, 1996). In that year only 56.3% of people with disabilities were participating in the labor force through working or looking for work. Of those people who were not participating, 56% had work potential or identified an environmental barrier that kept them from seeking employment. Environmental barriers might include, for example, negative attitudes or lack of physical access to buildings. Of those people who were not looking for work, 21.4% feared that they would lose income support once they were ever considered employable, a fear that is often well-founded (Fawcett, 1996). Almost half of those people between 15-24 years of age who were employed felt that their skills and education were wasted in the positions they held within their workplaces.

Many people with disabilities live in poverty. Statistics indicate that 21.9% of adults with disabilities are poor and these numbers rise to 25% for
women with disabilities and 31.2% for people who have disabilities affecting speech (Fawcett, 1996). These figures, however, may lead one to underestimate the extent of the problem since they do not take into consideration the proportion of income that is spent on disability-related expenditures. Approximately 36.4% of people with disabilities have such nonreimbursed expenses. Poverty is obviously linked to employment status, and both of these variables are influenced by the cumulative effects of disadvantage throughout a lifetime (Fawcett, 1996).

Notions about disability, that is the social constructions of disability, pervade our culture and social policy, influencing the quality of life of people with disabilities. In the case of employment and social assistance, the two most influential misconceptions are: a) that disability alone prevents employment rather than problems that arise from the interaction between the individual and an environment; and b) that disability is static, when, in fact 44% of the people surveyed experienced a reversal in disability status from the previous year (Fawcett, 1996).

Poverty, environmentally produced stress, and restrictive policy often leave people with disabilities feeling powerless. Further, powerlessness is an objective phenomenon where people lack the means to gain greater control and resources in their lives (Wallerstein, 1991). Based on her review of the literature, Wallerstein concluded: “studies suggest that being poor, low in the hierarchy, without control, and living in chronic hardship -- in other words experiencing powerlessness -- is a broad risk factor that increases susceptibility to higher morbidity and mortality rates” (p. 199).
Models of Disability

Medical and Charity Models of Disability Support

Kretzmann and McNight (1993) have argued that the most commonly utilized human service approaches focus on a community’s needs, deficiencies and problems. Drawbacks also include the development of a fragmented service system as people attempt to solve the many problems identified, the allocation of resources to service providers rather than to the residents of the community, the redirection of community leaders to emphasize deficiencies in order to gain funding for projects, and the fostering of relationships with experts as problem solvers, who are often people outside of the community.

The deficit-based approach also focuses on the maintenance of isolated individual clients rather than on the development of a broader community plan that incorporates the energy, intellect and creativity of community members. This approach, according to Kretzmann and McNight (1993), leads to the social construction of community members as needy, of their communities as troubled and of service providers or university researchers as the experts who can solve these problems. The community of disabled persons may benefit from the adoption of an approach based on assets rather than deficits.

There has been a proliferation of organizations “for” not “of” people with disabilities, which arguably serve the professional career needs of service providers (Oliver, 1983). Such services frequently operate from a medical model of disability that places the source of problems with individual deficiencies. Likewise, a charity model has also been criticized for grossly misrepresenting people with disabilities (Morris, 1991), creating a
culture dominated by images of people with disabilities as passive and dependant (Hill, 1990).

Many disability groups, advocates, and academics have called for a social theory of disability which places problems within the context of social organization (Oliver, 1990; Woodill et al., 1992). As part of this approach, the social construction of difference is recognized. The barriers or handicaps that people with disabilities experience may, according to this view, be primarily due to mainstream attitudes and established institutional policies more than an impairment in ability. This new approach to viewing disability is fundamentally at variance with both medical and charity models of disability.

**Newer Models of Disability Support: Independent Living Models**

Spokespersons for disability organizations have increasingly articulated their desire for a greater level of involvement in addressing the issues that affect them directly, such as the provision of disability-related services (Beresford & Campbell, 1994) and research (Woodill et al. 1992). A self-help model of Independent Living that involved people with disabilities in directing the terms of their own attendant care services arose from a group of students at Berkeley in the 1960s. This model included elements of peer support, attendant-care referral and training in independent living skills (DeJong, 1979). This movement came to Canada in 1980 and now there are over 20 Independent Living Resource Centres across the country. The centrepiece of this model is the notion that people with disabilities are the best judges of their own interests and therefore should have the
predominant say in determining what services are provided in the disability service market (DeJong, 1979).

Proponents of Independent Living Models have faced some criticism because of their use of an economic model that emphasizes service providers and individual service consumers with relatively little attention paid to the sense of a community of meaningful relationships (Woodill et al., 1992). Community, however, is emphasized by Kretzmann and McNight in their asset-based approach to building healthy communities. The psychological sense of community exists when "we yearn to be part of a larger network of relationships that would give greater expression to our needs for intimacy, diversity, usefulness, and belongingness" (Sarason, 1974, p. 3). As described by Woodill et al. (1992), a community model of Independent Living would recognize partnerships and relationships with many people, not just service providers, and these relationships would be reciprocal and based on equality of human status. Carpenter (1988), a founder of the Independent Living Centre in Toronto, incorporated the idea of empowerment in society for people with disabilities. Thus a newer Independent Living Model includes notions of community, partnerships and empowerment.

**Health Promotion**

Many health-care providers, community psychologists and institutions have recently been espousing the benefits of approaches that involve community members in addressing a range of issues affecting health (Giesbretch & Ferris, 1993; McKinlay, 1993; The Royal Society of Canada, 1995; Woelk, 1992). Although some have equated this approach with community development, one can make a distinction between community
development and community-based services (Labonte, 1993). Programs that link individuals or groups to health services within an existing service structure represent one important approach to health care, but these are distinct from community development projects which involve efforts to bring about change in sociopolitical conditions.

There is a connection, however, between the community-oriented approach and empowerment. In order to understand empowerment, Rappaport (1987), a community psychologist, stated that one needs to know about who and what people have authority over. He defines empowerment as a multilevel construct involving individuals, groups, organizations, communities and social policies. Empowerment is thus historically, culturally and locally situated. Theories about power as discussed later in this chapter may be useful in informing an examination of whether people with disabilities are truly empowered within the programs that are designed to serve their needs.

**Present Context of Partnerships in Canada**

Partnerships have permeated social policy vocabulary, advertisements, and calls for public involvement issued by government agencies and human service organizations (Boudreau, 1991). The 1990s in Canada have been described by Barnsley (1995), a community activist involved in community work related to violence against women, as a confusing period in which funders have required marginalized groups to form relationships with people that they do not agree with politically or even understand. Her description also accurately depicts the context in which work on disability issues has been taking place at a community level.
The Canadian government has established several initiatives (e.g., Disabled Persons Participation Program) that have promoted and required the use of a partnership approach as part of the criteria for funding of disability community projects and academic disability research. More recently, partnerships that support employment for people with disabilities have become the focus of funding criteria through, for example, the Opportunities Fund. One of these initiatives was a joint project between Human Resources Development Canada and the Social Sciences and Humanities Research Council. This program strongly encouraged academic researchers to form links with disability groups and service agencies. Although this initiative, which lasted five years, indicated to me a hopeful and positive development in funding policy, there were difficulties that were unaddressed, such as an insufficient definition of what partnership meant with respect to its practical development and use. Regulations, such as location of fund administration, also situated power with the university partner.

A trend has developed in Canada to attempt to involve consumers of health care services in the development of health care policy. This has taken place for example, in Ontario, Alberta, British Columbia, Nova Scotia, and Quebec through regionalization. Several of these efforts have been criticized as processes that have involved consumers in a token manner and that have created merely an illusion of local control (Mhatre & Deber, 1992). Sullivan and Scattolon (1995) conclude after reviewing several initiatives, that without devolution of power, flexibility in guiding policy and educational opportunities for all parties, effort will likely fail to meaningfully involve consumers. In particular, they suggests that educating
consumers and professionals on how implicit power hierarchies can interfere with the philosophy of consumer involvement would be valuable.

**Challenges of Partnership**

Most existing publications on partnership emphasize the economic benefits and lack critical political analysis associated with the involvement of disadvantaged groups (see Audet & Rostami, 1993). Government reports have been criticized as proceeding from overly simplistic notions of consumer involvement with no specification related to the roles they may play or acknowledgement of barriers (Sullivan & Scattolon, 1995). Other resources that incorporate some discussion of disability focus on establishing a working partnership between professionals and the parents of children with disabilities (see Dale, 1993). There is very little published literature regarding the evolution, structure and function of community partnerships that include people who belong to groups that are marginalized, such as people with disabilities (Lord, 1994; Scott-Taplin & Thurston, 1993).

Gray (1989), who has worked on developing collaboration theory, has suggested that conflict can be expected to play a role in partnerships as less powerful groups work to establish their legitimacy among other groups that have more power. Organizations of disabled persons and other partner groups should not be afraid of conflict, as it is through conflict that change occurs (Labonte, 1993).

The few investigators who have written about partnerships that include marginalized groups have identified several potential difficulties: different stakeholders within a partnership have been found to not share a
common theoretical or operational definition of partnership (Boudreau, 1991); the expertise of people with disabilities is often not acknowledged by professionals (Lord, 1994); service providers are resistant to share power with service receivers (Church, 1996); some people with disabilities are fearful about speaking out against others (Beresford & Campbell, 1994); and representatives from marginalized groups such as women's groups may be coopted and exploited by more dominant partners (Barnsley, 1993).

Several authors have developed brief lists of factors to consider that may lead to difficulties in partnerships (Krogh, 1996; Labonte, 1993; Lord, 1994; Woodill et al., 1992). Highlights of these contributions include Labonte's statement that community workers have clear mandates to support community group partners without attempting to get them to 'buy into' the institutional partner's mandate and goal. Lord has suggested examining the beliefs about people and change that are inherent in the partnership projects. The Partnership Agreement Framework that I have developed covers seven areas that partners are encouraged to discuss early in (and throughout) the process; it raises the issues of how each partner will benefit, how the partnership relationship will be supported and what mechanism will be used to resolve conflict (see Appendix A).

Theories of Power and Subordination

Theories about power are particularly relevant to the examination of community partnerships that include people with disabilities with others who are in positions that are socially, institutionally and historically associated with greater levels of power. This study has therefore been
conceptually grounded in the following theories on power and subordination.

Lukes (1974) summarizes three theoretical models of power. The one-dimensional view of power is represented when A has power over B to the extent that he can get B to do something that B would not otherwise do (Dahl, cited in Lukes). This model has been criticized because it is limited to the overt behavior and its influence on explicit decision making. This approach assumes that conflict is overt. The two-dimensional view of power can be illustrated by a scenario in which A makes decisions that affect B while also reinforcing social and political values and institutional practices that A considers important. B is prevented from bringing forward issues that might be detrimental to A’s set of preferences. This approach has also been criticized for limiting the analysis to observable conflict.

Lukes presents a three-dimensional model as more comprehensive. It considers not only observable behavior and conflict but also the social forces, institutional practices and individual decisions that serve to keep potential issues out of political discussion. This model acknowledges the existence of latent conflict inherent in the contradiction between the interests of those who exercise power and those whose real interests are excluded. The members of the latter group may not express or even be conscious of their interests. This last theoretical model of power provides a sociological and not merely personalized explanation of how power operates (Lukes, 1974). The three-dimensional model appears to be one of the most relevant to the examination of the experiences of people with disabilities in their interactions with others in partnerships because it moves beyond a
focus on individuals to the broader social context in which handicaps are typically created overtly or covertly.

Bourdieu and Passeron (1977) have written extensively about the processes involved in the reinforcement and replication of the dominant relations of power in society. They identify oppression as the imposition of meanings in a manner that conceals the power relations which give it force. In fact, social dominance is successful only when it achieves its effect while remaining unrecognizable. Bourdieu's model emphasizes the arbitrariness of the content imposed since it cannot be deduced from any principle, such as all persons who have a disability lack the skills to effectively communicate with collaborators with partnerships. Bourdieu and Passeron bring to the reader's attention the political and historical circumstances that have led society to a situation where power relations have become increasingly masked. This literature may have implications for this study in terms of the use of promoted partnership practice where in fact power relations among members may be obscured when the collective is emphasized.

In a manner similar to Freire's model that is described below, Bourdieu and Passeron (1977) describe a situation in which members of the oppressed group recognize the principles of the dominant culture as legitimate and impose self-repressive censorship practices to ensure that they are not challenged. The threat of exclusion is used as a means of influencing people to adopt the dominant relations of power. This point is relevant to the struggle among people with disabilities who apply differing belief systems when they use various approaches to bring about individual
or social change, including some that would appear to reinforce rather than challenge the status quo.

Freire (1993) has become a prominent figure in the academic world through his unique combination of theory and practice of a liberation pedagogy. His work in the fields of adult education and literacy training has been grounded in his experiences with poor and illiterate people of Brazil and Chile (Torres & Freire, 1994). However, his approach has been widely applied in a less economically developed context, and there have been efforts to explore and incorporate some of the participatory principles and precepts into education, research and social development in North America (Findlay, 1994; Gaventa, 1988).

In Pedagogy of the Oppressed, Freire (1993) outlined major concepts such as oppression, suboppression, conscientization and dialogue. The oppressed, Freire argued, have to resist becoming suboppressors (i.e., oppressing others as a result of being treated in an oppressive manner). Conscientization is the development of critical awareness of the nature of oppression and developing a commitment to end it. It is fostered through the practice of critical pedagogy (Freire, 1993; Simon, Dippo, & Schenke, 1991; Shor, 1992) which necessarily involves dialogue. The concept of dialogue refers to the constant exchange between the teacher who facilitates this awareness and the students who are involved, acknowledging the ability of both parties to develop understandings of the world and take action to change it (Freire, 1993).

Liberation and humanization, the experience of feeling fully human, will not take place, it is proposed, if the roles of the oppressed and oppressor are reversed. Rather, what is required is the formation of new
relationships among human beings. This would appear to be relevant to the study of partnerships where people from different sectors of society may be struggling to alter the relations of power and develop new ways of relating to one another. These concepts relate to domination which has been identified as a fundamental theme of our epoch and liberation as a central aim of research on the oppressed (Friere, 1993; Vernon, 1997).

Principles of critical pedagogy overlap with principles of feminist theory and pedagogy. Consistencies are clear in Weiler's (1994) statement that "feminist theory, like other contemporary approaches, validates difference, challenges universal claims of truth and seeks to create social transformation in a world of shifting and uncertain meanings" (p. 12). Both approaches recognize that issues related to oppression, consciousness and history underlie the ultimate goal of social transformation.

Feminist theory, Weiler (1994) argued, can enrich Freirean goals of liberation in several ways. The teacher-theorist and students of critical pedagogy should situate their historical struggle and themselves in terms of personal identity and oppression roles. Those who are oppressed do well to remember that they can, at the same time, come to a position where they are oppressing others. Weiler has described the use of discussions of personal experience and feeling as the basis for forming critical consciousness in a manner that illuminates commonly accepted assumptions in society that act to divert our attention from the truths of people's realities. Profit, linear power, and institutional dehumanization act to destroy the expression of feelings (Lorde, 1984).

The feminist movement, which has been criticized for assuming a white middle-class focus (hooks, 1984; Ng, 1993), has provided valuable
lessons about power. Of relevance to this study are the writings that express the perspectives of women who are black (hooks, 1984), lesbian (Lorde, 1984), immigrant (Ng, 1993; Ng & Ramirez, 1981), and disabled (Wendell, 1996). These authors provide insights relevant to the experience of living with a differently abled body, in a sociopolitical environment that is restrictive, if not oppressive. People with disabilities who are trying to become more conscious of the power relations that influence their lives must confront a complex set of forces that encourage conformity to the status quo. People with disabilities also struggle to recognize, among themselves, their commonalities and differences in terms of other identity locations such as gender and ethnicity.

The writings of bell hooks (1984) brought attention to the difficulties that have arisen in the feminist movement when women were assumed to be a homogeneous group that could be represented merely from the experience of white, middle-class women. She has challenged the assumption that women would (as a result of their biological difference) have the same approach to viewing and using power. It is unfortunate, she argues, that some women have taken to obtaining positions of power as a means of altering the relations of power, since the promotion in power status requires an acceptance and reinforcement of the dominant relations of power that keep some people oppressed.

The analysis proposed by hooks (1984) appears to be pertinent to the expected role that people with disabilities are frequently expected to play in partnerships as representative of a group of people who vary along many dimensions including disability type, class, gender, and race. Hooks has identified the potential for people within groups to exclude others who in
some way share a membership in the group. Such an analysis appears to be applicable to the experiences of people with some forms of disability who feel oppressed by people who hold more dominant positions within the disability hierarchy.

Lorde (1984) outlined three ways people react to difference: they ignore it, copy it when it is dominant or destroy it when it is subordinate. The dominant group's expectations that the oppressors will teach them about oppression functionally results in a situation where the oppressors evade responsibility and the oppressed are diverted from more constructive activities. Consistent with the feminist belief in acknowledging difference, Lorde has stated that "too often we pour the energy needed for recognizing and exploring difference into pretending that those differences are insurmountable barriers, or that they do not exist at all" (p. 115). This may result in voluntary isolation or false and dangerous connections. Her ideas appear relevant to exploring the reactions of people with disabilities to the request for involvement in partnerships; some may regard partnerships as unfruitful in terms of their broader political goals. Her work also has implications for partnership groups since the partners have to decide how much to focus on the common goals versus the differences among the partner groups being represented.

Consider the experience that black women and men have of being used by the "power structures" to work against one another. There is a need to separate the interests of the oppressor from the conflicts that may exist within communities of people (Lorde, 1984). White women may, because of their shared race with white men, be more vulnerable to joining the oppressor under the pretense of shared power. These linkages between
personal identity, community location and the dominant relations of power in society may be relevant to a discussion of partnerships that include people with disabilities who have to negotiate these dimensions as they work with others in community partnerships.

Ng (1993), from her specific position as an academic, has insisted on bringing a feminist perspective to race and ethnicity issues and a minority perspective to gender studies. In her work she avoids treating race, gender, and class as categories that are static. Instead, these categories are considered to be social constructions formulated in a manner involving activities over time and space. Class, for example, is described as a process that reflects how people construct and alter their relations with respect to the production and reproduction of societal forces (Braverman, 1974). Ng recommends consideration of Gramsci’s (see Sassoon, 1982) notions of “common sense” as representing the taken-for-granted nature of ideological thinking. People in society are frequently unconscious of notions that are socially hidden but have a strong influence over social behavior including racism. The above insights are useful both in terms of the way people with disabilities may come to understand themselves and the way they are understood by others. The approach is also relevant to exploring the process of discrimination that people with disabilities may experience in their interactions with others within community partnerships.

A disabled feminist, Wendell (1996) has made a significant contribution to the literature in several areas including viewing disability as a form of difference. In relation to disability, she describes the process of “othering,” that is, viewing people as distant objects rather than as active subjects to whom nondisabled people can relate (similarly see Ng, 1993).
Persons with disabilities often represent for nondisabled people, the rejection and fear associated with imperfection, failure to control the body, and everyone's vulnerability to weakness, pain and death. People should be challenged to view disability as difference rather than tragedy. Such concepts related to the way people with disabilities are viewed by others are relevant to a study of their struggle to work with nondisabled people through partnerships.

Social construction plays a large role in the formation of disability (Oliver, 1990; Wendell, 1996; Woodill et al., 1992). Within this framework, people who may live with impairments do not necessarily experience limitation. Handicaps are conceived of as rooted in the beliefs about disability that pervade society and result in negative stereotyping. As discussed earlier in this chapter, many people with disabilities have perceived that these types of barriers have prevented them from looking for or finding work. In partnerships where roles must be negotiated, it would be important to consider the influence of social constructions and stereotypes about the nature of work that people with disabilities are expected to contribute. Since social construction emphasizes the created environment, it would appear relevant to the study of partnerships in which the partners can play a direct role in reducing handicaps experienced by people with disabilities.

The call for a social theory of disability that views the situation of people with disabilities in terms of the concept of oppression has been made by many people with disabilities and academics in the field of disability studies (Abberley, 1987; Oliver, 1992; Woodill et al., 1992). Abberley has argued that for an understanding of the sociology of disability, we must
learn from the study of racial and sexual inequality. Disability, however, plays a somewhat different role in the process of oppression in present Western societies than other forms of difference since there is an impairment involved. This biological difference is often incorporated explicitly into the arbitrary ideologies (cf. Bourdieu & Passeron, 1977) that serve to keep people with disabilities in an inferior position. Although disability can be to a large extent seen as socially constructed, real differences in specific abilities should not be denied within a theory of disability as oppression. This point can be illustrated when considering a situation where a person who is nondisabled thinks that they are giving a compliment when they tell a person who has a disability that they are not considered disabled, resulting in a negation of a central part of their identity.

**Research on Methodologies for Investigating Disability**

This study of the experiences of people with disabilities in community collaborative partnerships has been methodologically guided by others, in particular the works of Michael Oliver (1992), Paulo Freire (1993), Budd Hall (1975) and Patti Lather (1986a; 1996b). It is important to state, however, that the extent to which I was able to implement an empowering or emancipatory form of research was constrained by my location within an academic institution.

Oliver (1992), an academic and activist who has a disability, has made a resounding call to change the social relations of research production which place the researcher in the role of expert and constructs the person with a disability as the passive research object (also see Barnes & Mercer,
Researchers should use their skills and knowledge to frame their work as "part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives" (Oliver, p. 102) rather than reinforcing the oppression experienced by people with disabilities.

A distortion takes place when researchers develop questions in isolation from the direct experiences of disability (Oliver, 1992). Such questions almost inevitably reflect an individualistic perspective of disability rather than the social constructionist perspective that is more common among people with disabilities themselves; i.e., the problem to be studied is with the limitations of the disabled person's body and not with the attitudes and other barriers that exist in society. The concept of alienation which has also been described in relation to nondisabled participants in research (Rowan, 1981) is relevant to disability research where restricted behaviors are used for the purpose of research and not as part of a participant's life goals.

Following his critique of standard research methods, Oliver (1992) has proposed the use of emancipatory research as an alternative. He draws on the work of Paulo Freire and feminist Patti Lather (1986a, 1986b) in constructing his own model. Within this newer paradigm, the researcher highlights life experiences and struggles while using theories that are open-ended, nondogmatic, informing and grounded in the everyday circumstances of life for those involved. Oliver has brought attention to the need to develop methodological techniques based on the emancipatory research paradigm for use with people with disabilities.
The academic and community work of Oliver, although based in England, has had a significant impact on the research expectations of disability organizations in Canada (Krogh & Petric, 1994; Woodill et al., 1992). From this work, I decided that I should make my doctoral research relevant and of direct benefit to people with disabilities, while also supportive of change at a personal, social or policy level. A process was envisioned that would bring people with disabilities together rather than alienate them.

Participatory action research (PAR) is considered a particularly relevant method for use with marginalized persons (Maguire, 1987; Park, Brydon-Miller, Hall, & Jackson, 1993; The Royal Society of Canada, 1995). Budd Hall (1975) defined the central principles of participatory action research as follows:

1. That research methods have ideological implications;
2. That research should be of some immediate and direct benefit to the community involved;
3. That the community should be involved in the entire process of research from the formulation of the problem to the discussion of how to seek solutions to the interpretation of findings;
4. That if the goal is change then the research team should be comprised of those people in positions to bring this change about;
5. That the research process should be seen as a total educational experience which serves the needs of the established community and increases awareness and commitment within the community;
6. That the research process should be viewed as a dialectic process like a dialogue over time rather than as a static plan; and
7. That the object of the research process should be the liberation of human creative potential and the mobilization of human resources for the solution of social problems.

Participatory action research is an approach that links research with education and action (Brown & Tandon, 1983; Cornwall & Jewkes, 1995; Hall, 1981, 1984), although in practice this process can be complicated. Hall (1975) argues that complexity can lead to an even more accurate picture of the reality in which we live than we would otherwise obtain. Hall’s work influenced the present study with respect to finding a community site where the study of partnerships was relevant and involving an organization as a research partner.

Paulo Freire (1993), whose work and theory of power has been described earlier in this chapter, also influenced the methodology of the present project. He and others who have written about power helped me to consider possible forms and roles that power relations that include people with disabilities may take in society and in partnerships. I was led to consider ways that I might act as a facilitator/educator in a process designed to develop critical thinking skills and motivate action among people with disabilities. My ideas of critical pedagogy, particularly the need to use an openly critical and reflective process, have also been influenced by the work of others such as Giroux (1992), Shor (1992) and Simon, Dippo, and Schenke (1991).

Lather (1986b) has explored emancipatory approaches to generating knowledge in her well-recognized article on research as praxis. Her ideas like those of Freire (1993), Hall (1975), Ng (1993), and Oliver (1992) overlap to some degree. Research is understood to be socially constituted,
historically embedded and values-based. The goal of such an approach is to increase people's consciousness of the contradictions in everyday understandings and how this new knowledge may in turn lead to transformation.

Power and empowering pedagogy are recognized as critical to an emancipatory approach. Giddens (1979) states that the task of critical social science is to explore the nature of choice versus constraint and therefore to centre on questions of power. Lather (1986b) proposes that researchers working within this framework view empowering pedagogy as an essential step in the social transformation that it identifies as a goal. In this process both the researcher and the participants are changed through self-reflection and a deeper understanding of their situations.

Lather (1986a, 1986b), like Hall (1975), emphasized the need for reciprocity in a research relationship. Emancipatory researchers, she argues, consciously use their research to help participants understand and change their situations. Critical inquiry is a response to the experiences, desires and needs of oppressed people (Fay, 1975), and therefore it is essential to work to understand the world view of the research participants. There is a crucial step beyond articulating what participants know; they should be encouraged to collaboratively theorize about what they know.

It is a crucial time for the development of strategies for linking critical theory and empirical research (Lather, 1986b). This recognition that there is no standard approach and in fact that there are limited documented possibilities, gave me permission, in the design stages of this study, to listen to what made sense to me from both my positions as an academic
researcher and as a community activist, with consideration of the people involved and the broader sociopolitical circumstances.

**Research Questions**

The review of the literature guided me in developing more specific questions regarding the experience of people with disabilities in community partnerships. These questions included:

1. How do people with disabilities experience the social construction of disability?
2. How do they experience constraints in the process of work?
3. Is their life-based expertise acknowledged and accepted by others?
4. How has heterogeneity within their group had an impact?
5. How have internalized oppressive structures been reproduced within their group?
6. How have they consented to dominant relations of power?
7. How have they challenged dominant relations of power?
8. What positive visions do they have about equitable relations?
CHAPTER 3

METHOD

Introduction

Within the qualitative, action-oriented approach previously mentioned, this chapter describes the specific steps that were taken to gather and interpret data: identifying a research site, establishing a working relationship with a community research partner, addressing ethical considerations, collecting data, analyzing and interpreting it, and drafting the present thesis. The chapter concludes with a summary of the ways that the study design took into account the criteria for qualitative research outlined in the previous chapter.

This study, which has three main phases, began with the establishment of a collaborative research partnership between me and a representative from a disability organization that shared an interest in collaborative community partnerships. This organization designed partnership workshops to bring together disparate parties to explore the possibility of developing a partnership for a limited period of time to address a specific disability-related issue. For the purposes of the study, I acted as a participant observer during two such partnership workshops of 4.5 and 3 days, respectively; these workshops defined phases one and two of the project. At the end of each workshop, I interviewed participants about their experiences of living with a disability. In particular, I was interested in
eliciting information about the nature of their interactions with nondisabled people including the service providers with whom they typically interacted frequently. Beliefs about disability were explored with nondisabled participants. Their theories or explanations that they used to understand the interactions were also of interest to me. Many questions focused on their ideas of collaborative community partnerships that include people with disabilities, using the common experience of the workshop as a reference point for concept explorations. A summary report of the major themes that emerged from the interview data was distributed to the participants and the partner organization within six weeks of the workshops.

In the third phase of the study, ten leaders representing people with disabilities in a wide variety of collaborative community partnerships from across Canada were involved in a four-day workshop to examine, analyze and verify the major issues regarding people with disabilities and partnerships that were identified in the first two workshops. The person representing the partner organization co-facilitated the workshop with me. We worked to involve participants in creatively expressing their practice-based theories of partnerships. Participants were also supported in developing an action plan for their partnership project based on what they learned during the workshop. The three workshops that corresponded with the three phases of the study spanned a period of approximately 2.5 years. Data analysis was carried out for one year thereafter. During the whole three-and-a-half-year thesis project, I kept a journal as a tool to facilitate reflection and to document the study process, research dilemmas, and my evolving understanding of collaborative community partnerships.
Research Site, Data Collection and Negotiating Terms of Participation

Identifying a Study Site and Community Research Partner

After giving a presentation on partnerships at the National Independent Living Conference in August, 1994, several conference participants involved in a variety of projects within a single community invited me to visit their town because of the residents' active interest and involvement in using community partnerships that include people with disabilities. They knew that I intended to study this topic for my dissertation and that I was looking for a possible site for the study. I did not know any of these people, most of whom were people with disabilities, before this conference. During this excursion, I paid for my travel expenses and someone from the community allowed me to stay in her home. My hope was to discover a mutually beneficial arrangement in which I could study partnerships for my dissertation while supporting people with disabilities who were genuinely interested in the topic of partnerships.

During my week-long stay, I attended approximately 10 meetings representing 7 projects in which people with disabilities had some kind of role. During this period I tried to remain open to all possibilities and reflected on which of these projects might be appropriate for this thesis. Some were eliminated as possibilities because (a) their scope was too large, or (b) the role of people with disabilities was too tentative, or (c) there did not appear to be an interest in my involvement as a researcher. This process required a great deal of patience.

By the end of the week, a project was identified, along with a partner organization and contact person from this organization. These arrangements arose from several exploratory meetings with a disability
organization that had plans to conduct a partnership-building workshop. The organization coordinating the workshop was a cross-disability, consumer-directed organization. The organization's mandate and structure addressed my concerns, as outlined in Chapter 2, that relate to having an adequate system for representing cross-disability issues at a community level. This organization had a particular interest in community partnerships and had previously conducted at least one workshop designed to build a community partnership to address a disability-related issue. Further, it seemed likely that there would be future opportunities for study and for community-based action.

The organization's executive director, who would act as my main contact person, was friendly, sensitive to issues of invisible disability, and open to the idea of participating in research. This woman also appeared to be very thoughtful and cautious about interacting with people outside of the organization, taking her position as a representative of people with disabilities extremely seriously. I knew that her approach could create challenges in an already demanding circumstance of trying to bridge academia and community goals in research. My impression was that if I made significant errors, the project would be terminated. I felt that this would be an appropriate environment to test the use of a research partnership approach. I expected to learn more about research partnerships as a form of collaborative community partnership and about the implementation of the methodological principles outlined in the previous chapter. I believed that working with strong linkages with people with disabilities would allow me to be better able to capture their perspectives
and that my personal experience at the community level might place me in a unique position to explore with insight such perspectives.

**Negotiating Terms of Participation and Ethical Issues**

Clear working roles and expectations are an important part of establishing a strong research partnership (Krogh, 1996). The Partnership Agreement Framework outlines seven main areas such as roles, responsibilities, conflict resolution mechanisms and finances (see Appendix A). The PAF was used as a guide for me and the organization representative to develop a written agreement outlining the terms of our working relationship. After several drafts, the agreement was presented to the board of directors for review and approval. This process was undertaken prior to each of the workshops which formed the basis of each of the three research phases (see Appendix B to view a sample partnership agreement). The board of directors of the research partner organization requested that a change be made to the first agreement. This change, which was that I would pay for the entire costs of conflict resolution if it was needed, rather than for half of the cost, was incorporated into the subsequent two agreements.

The organization representative and I met twice to discuss ethical issues related to research in general and to this project in particular. We focused our discussion on the people who would be participating in the workshop, the topic being explored, and the small community context. In an effort to equalize power, I provided my research partner representative with a comprehensive but easy-to-understand book chapter by Seidman (1991) on ethical issues in research and informed consent. This allowed her to review the issues from her perspective and raise them in our discussion.
Our discussion of general ethical issues eventually led to more specific issues related to the development of the informed consent form. I drafted an informed consent form that was reviewed by the organization representative (see Appendices C & D). After she had time to review it and consult with others as needed, she returned it to me with suggested changes. In this way, the community research partner was involved in establishing an appropriate level of confidentiality after careful consideration of the vulnerability of some of the participants, the topic being explored in the workshop, and the community setting involved. An administrative consent form was also developed for the organization to sign.

The fact that I was conducting a study was introduced to participants early in the workshop planning. In addition to stating my role as researcher I also shared my affiliation with an organization representing cross-disability issues. The participants knew from the beginning that they could choose not to participate in the postworkshop interviews. Any concerns related to my involvement could be expressed to the facilitators directly or through the daily written or verbal evaluations. As a few participants in the first two workshops indicated some concern about being tape recorded during the workshop itself, no recording took place.

Before each of the tape-recorded interviews each participant was asked to sign an informed consent form. At the beginning of each postworkshop interview, I carefully explained all of the terms of the informed consent to ensure that the level of confidentiality and measures taken to protect confidentiality were adequate. This was particularly important for some members of the first workshop who were considered by the partner organizations to be “vulnerable.” For example, one participant
had a cognitive disability, so very concrete and simplified examples were used to illustrate concepts. Modelling was used to explain that he could say "Stop," "I don't want to answer that," or "I want a break." This interaction was tape recorded.

**Research Phases**

This study comprised three major research phases or cycles, each consisting of data gathering, analysis and theorizing. The three workshops are the central component of each phase. The three phases are described below in relation to the workshop, interviews, other data collected, and follow-up analysis.

**Phase One**

**Workshop 1: Guardianship**

This workshop brought together people with disabilities, seniors, and service providers to examine the implementation of a community-wide response to guardianship issues affecting people who may not always be in a position to make choices for themselves. The participants were all residents in a local area who were chosen by the staff of the disability organization that acted as a partner in this study. The workshop covered relationship issues such as the assumptions people make about one another through stereotypes, guardianship issue exploration through role-playing scenarios, and concrete action-plan development. It was in part based on a reverse integration model (Hill, December, 1995, personal communication).

The group met in a comfortable, accessible building on the edge of the small community where the participants lived. Lunches were catered,
allowing the participants to interact informally during periods of time that were not part of the structured workshop. This workshop took place during the daytime, from Monday through to Friday. Due to poor weather on Wednesday only half of the participants were able to attend and they chose to leave after lunch.

The participants, according to the staff involved in the selection process, were thought to have represented people who would likely be affected by the issue of guardianship, either as a result of living with a disability or as a result of being in a position of providing support to someone with a disability through their paid employment. Those in the workshop represented a variety of disabilities and degrees of disability; they included persons who had a disability related to a brain injury, hearing, developmental delay or mental illness. One participant was nonspeaking, and another represented a group of senior citizens. Service providers included a health administrator, a nurse and two personal care workers.

During the workshop, I acted primarily as a participant observer; at the request of the partner organization representative, I facilitated one activity that encouraged participants to explore their thoughts about partnerships and prepared daily evaluation forms for the participants. Daily evaluations were summarized and given to the facilitators so that they could plan modifications the following day accordingly.

Follow-up Interviews

All of the participants were asked to consider being interviewed, and all but two agreed. In total, six interviews were conducted (see Appendix F for question guide). Modified procedures were used with some of the
participants. With one of the participants who has a developmental delay, I used modelling to demonstrate how he could request a break from the interview. He was able to use these modelled statements to state that he wanted to take a break. At his request, he took me for a walk down the street where he showed me places that were familiar to him. Another participant, who had no reliable communication system, was interviewed simultaneously with a man who knew the participant through years of work in the participant's group home as a personal care worker and later as the supervisor of the group home. The care worker also participated in the workshop. In this manner, the worker did his best to answer the questions as best as he could on behalf of the participant and raised issues that he felt affected the consumer participant. On occasion, he would provide his interpretation of the participant's vocalizations or movements. This particular interview was later removed from the data set because the information gathered was too vague and could not be assumed to represent the views of this participant who had severe disabilities.

The interviews took place between one and two weeks after the workshop, allowing participants to return to their community positions before reflecting on the workshop experience and partnerships. The location of these face-to-face interviews varied according to the preferences of the participants. The office of the disability organization was used for many of the interviews, but one was conducted at a participant's home, and another was conducted at the house where I was staying.
Other Data Collected

During this phase of the research, the other data that were collected included field notes kept in my thesis journal, notes reporting on long-distance telephone conversations related to the planning and follow-up of the workshop, transcriptions or notes from planning meetings, daily workshop evaluations, and content documents such as newsletters related to guardianship.

Follow-up Data Analysis

The interviews were transcribed and analyzed using qualitative thematic analysis, and a community report was produced for the participants. Guidelines for this report were established with input from the community partner representative. These guidelines resulted in a report in plain language that was limited to ten pages in length (not including appendices). I addressed sensitive confidentiality issues by organizing the paper into major themes so as not to reveal a participant's personal story. I also selected a variety of exemplary quotations to represent the ways that people viewed that issue. This report was distributed to each of the participants. The partner organization included this document in their final project report to the funders that was also distributed to each of the participants.

Phase Two

Workshop 2 - Women's Issues

This workshop brought together women from women's centres and women from disability organizations from across Canada to explore the
possibility of developing partnerships that would address issues of mutual interest. There were 12 participants, with 7 from disability organizations and 5 from women's organizations. All participants were selected by the staff of the research partner organization in collaboration with a representative from the women's organization. Participant selection was influenced by funder criteria. The workshop covered relationship issues such as the assumptions people make about one another through stereotypes, similarities and differences between the two types of organizations, guiding principles for their future work together, and concrete action-plan development.

This workshop was organized by the research partner organization for this study in collaboration with a network of women's centres. The same woman who acted as the research partner representative also acted as a workshop co-facilitator. The co-facilitators were a woman from a women's centre in the same local community as the research partner and a woman representing a national women's centre network. This workshop took place in a Canadian city close to where I live. The workshop was three days long with group lunches allowing for informal discussions. There were optional evening activities that also provided opportunities for the women to spend time together.

Most of the women from disability organizations were familiar with one another and in some cases had worked together through a broader organization that encompassed their organizations. Many of the women from women's centres also knew one another from occasional conferences or meetings. For the most part, the representatives from the women's centres had very limited experience working on disability issues or with disability
organizations, but some of the disability representatives had experience working on women's issues that affect women with disabilities through their own organizations and occasionally with women's centres.

Before and during the workshop, I assisted with matters such as arranging meeting room space. I facilitated an activity that would elicit participants' ideas about partnerships. On the following day I reported back the ideas that participants derived from small-group work. As in the first workshop, I was immediately introduced as someone who was conducting a study on partnerships that included people with disabilities. I was also introduced as a person who had been involved in the work of disability organizations. Several people from the disability organizations recognized me as someone who had a disability or at least had been quite involved in the work of disability organizations.

Follow-up Interviews

All of the participants were asked to consider participating in the interviews at the beginning of the workshop. I telephoned to request participation from women who showed some interest in being interviewed but who did not submit their consent. Of the participants associated with women's centres, three women were interviewed. In addition, three women from Independent Living disability organizations agreed to participate. All of the interviews were conducted over the telephone, using a speaker phone to enable tape recording. Most of the interviews took place within three weeks of the workshop.
Other Data Collected

During this phase, field notes were collected in my thesis journal. These reflected some of the issues that arose between the co-facilitators; for example, the woman representing the disability organization wanted to spend a significant amount of time on process issues relating to “getting to know you,” but the woman co-facilitator representing the women’s centres wanted to move quickly into concrete planning of actual or potential partnership projects.

I also interviewed the co-facilitator representing the women’s centre and briefly interviewed the woman representing the disability organization regarding the workshop. The research partner organization representative was quite reluctant to have proceedings tape recorded. This provided some data-gathering challenges during the first two phases of research in particular and, by agreement, no recording of any portions of the workshop was carried out. As a researcher, I thought it was essential for me to accept these conditions and work within these consumer-directed circumstances to obtain the available data needed for the study.

Follow-up Data Analysis

The interviews were immediately transcribed and analyzed using a qualitative thematic approach. The major themes were prepared in a draft summary report that was then distributed to the participants and the organization. The participants had one month to review the document. A few participants provided suggestions and reflections on the draft report before the final report was prepared. The partner organization included this
document in the final report to the funders that was also distributed to each of the workshop participants.

As in the first workshop, measures were taken to protect confidentiality. No names were used in this summary report, and the analysis focused on themes that arose in many interviews. In this way individuals' stories and individuals could not be easily identified. Direct quotations were used to exemplify the themes.

*Phase Three*

**Transition Period Between Workshops Two and Three**

Information from the first two workshops provided rich data regarding both the individual interactions within partnerships and the organizational issues that affect groups involved in partnership. During this transition period, the partner organization representative and I reflected on the findings and what action we wanted to take in the future together. During this time we also initiated and obtained funding for a separate research project: a project to examine strategies to support the operation of disability organizations. We worked together to continue to address collaboration issues associated with this new project, i.e., building trust, recognizing different forms of expertise, sharing power and altering the power relations within research.

After a period of reflection and discussion, we decided to design a third workshop to share what had been learned from other community members through the thesis-research activities and to further examine partnership issues. We spent six months preparing and modifying our proposal in order to obtain funding. We involved Beyond Consulting Inc., a
company composed primarily of entrepreneurs with disabilities who facilitate community development projects. They assisted with meeting the funding criteria that the workshop project support the development of employment-related skills of the participants with disabilities. Their involvement included assisting with the implementation of the workshop and being a resource to participants as consultants.

Phase three was significantly different from phase one and two in that I was involved, from the beginning, in designing the workshop; I was responsible for developing the workshop curriculum. This allowed me to design the content of the workshop in accordance with my research goals. By this time, I had become quite familiar with community perspectives of partnership issues and the workshop processes that my co-facilitator would be comfortable with, and these were considered in the design of the curriculum. The draft curriculum was reviewed and approved by the research partner representative and a representative from Beyond Consulting Inc.

Workshop 3

Nine of the ten participants of this third workshop were working in their own communities as a representative of people with disabilities in a community partnership. One person was working in partnership with people with disabilities from her employed position within a service agency. The partnerships addressed issues such as health care, social policy, development of assistive technology, and community organizing. Geographically, participants represented nine of the ten Canadian provinces. The type of sectors involved in these partnerships included
government, social and health services, academic, First Nations, women's centres, multicultural groups, technology developers, and nonprofit organizations. Nine of the participants had a disability.

The amount of experience with community partnerships and their level of enthusiasm or hesitation about partnerships varied; I wanted to test the application of preliminary theories about partnerships in many settings and among people who held a variety of beliefs about partnerships, not just committed supporters of partnerships. A brief description of the participants and their community partnership projects is provided in Appendix F.

The one person who was able-bodied was included for several reasons: she met most of the other criteria explained below; she had expressed a great interest; most importantly, she agreed to use her skills to ensure that one of the other participants who had a disability affecting vision and learning could be fully included. She provided plain language translation of written material, whisper translation, prompting and guiding. Several participants were also from diverse ethnocultural populations, however the majority were white Anglo Saxon. During the workshop people were asked to represent their own personal view and experiences, and where appropriate, the experiences, philosophies, approaches of the organization and partnership to which they were affiliated.

Workshop participants were selected by the research partner organization's representative according to a set of criteria that I was involved in developing. The criteria reflected a desire to have a diverse group of participants in terms of the geographic region of Canada in which they lived, their cultural background, the sectors involved in the partnership and
the topic being addressed. When considering individuals we looked for people who were currently representing people with disabilities in a collaborative community partnership. We also considered their skills and interest in conducting follow-up work. A notice was published in a national disability magazine. People who expressed an interest were sent a more detailed description. Prospective participants were asked to submit a letter outlining how they intended to apply the partnership training within their community. They were also asked to submit a letter of support from someone representing the collaborative community partnership, indicating an interest and willingness to support the participant in conducting follow-up work.

The third phase had several purposes. To satisfy funding requirements, the project was portrayed as developing skills among participants with disabilities from across Canada so that they could move into jobs that required knowledge of community collaborative partnerships and partnership negotiation. From the perspective of the partner organization, one of the additional central goals was to provide direct support to consumers in their work of representing people with disabilities in community partnerships. In terms of the goals of the thesis research, I viewed this workshop as a crucial opportunity to corroborate and validate the themes derived from phases one and two. It was also an opportunity to see how well central issues applied to a variety of settings beyond those explored in phases one and two. The participants attended to learn more about partnerships that include people with disabilities.

This four-day workshop took place in a major Canadian city and was co-facilitated by the research partner representative and me. We received
volunteer assistance from three small group facilitators from Beyond Consulting Inc. The participants were divided into pairs of learning partners at the beginning of the workshop with the intention of facilitating the development of a relationship that could lead to reflection during the workshop. Although some activities on the first day were done in pairs, the participants changed working-group composition and size during the activities scheduled on subsequent days.

The idea of learning partners came not only from my training in adult education and my facilitation experience but also from two of the participants who naturally formed a learning partnership prior to the workshop. The activities, such as role play, mural making, and discussion of a metaphor were designed so that participants would have to draw upon their own experiences and understandings of partnerships in a process of individual or collective theory generation. For example, paired participants were asked to draw a picture representing partnerships. One group grew a tree. Its many roots represented the consumers in the community who provided stability and relevance to the partnership project. The funders provided the fertilizer allowing the tree to grow and the sun represented mutual respect. The branches of the tree represented the many possible issues that such a partnership could address. In this manner, participants were guided through a process of identifying, representing and expressing the elements of partnership that they considered central.

Stages of Preparation for Workshop 3

In order to illustrate the practical implementation of phase three, the main stages of planning are outlined below. The curriculum was designed
to encourage participants to explore and address the major dilemmas that emerged from previous research interviews conducted in phases one and two. The curriculum was reviewed by two members of the disability community: one from the research partner disability organization; one from Beyond Consulting Inc., a group that acted as a third partner in this workshop project; and me.

A questionnaire was used to gather information about a variety of logistical and access issues for people with a variety of disabilities. This information was needed in order to ensure that the workshop was fully accessible to all participants, regardless of disability type. Participants were interviewed regarding their ideas about and experiences with partnerships. They were also asked questions about one particular partnership that they were presently involved with. Information from these interviews was used to further refine the training materials in order to meet the expectations of the participants and the needs of the research study.

A learner's contract was developed by each participant after their discussions with the facilitators. It was used as a way for participants to clarify their learning goals and their expectations for the workshop. The contracts also assisted the facilitators in modifying the curriculum and its implementation accordingly. Participant learning contracts were distributed to all participants and facilitators before the workshop, allowing participants to become familiar with one another, their partnership projects, and their learning goals.
Themes for Curriculum Content. The workshop activities were designed to cover the following major theme areas: How is "Partnership" Understood?, How is "Disability" Understood?, Benefits of Partnership, Risks of Partnership, Purpose of Partnership, Representing a Partner Group, Collaborative Adult Learning, Collective and Individual Voices, Inclusion versus Meaningful Participation, Social, Political, Economic Context of Partnerships, Cultural Issues in Partnerships, Power Relations in Partnerships, What Can Power Look Like in Partnerships?, How Can We Support More Equitable Partnerships?, and Creating Social Change through Partnerships.

Learning Experience. A variety of learning experiences were involved in the workshop. This creative approach assisted facilitators in involving participants with diverse learning needs and preferences while also introducing them to a range of techniques that they could use in their future work. These activities also provided participants with a means of producing indirect yet powerful descriptions of their practice-based theories of collaborative community partnerships. The techniques used in the workshop included sociometry, role play, mural making, body sculptures, lecture, story telling, exploring metaphors, as well as small, medium and large group discussion and activities.

Postworkshop Interview

The postworkshop interviews were used: (a) to gather reflective and evaluative information based on the workshop experience; (b) to gather information about follow-up activity; (c) to ask further questions about
their understanding of partnerships; and (d) to request clarification of understandings generated from the first interview. All workshop participants agreed to be interviewed.

Other Data Collected

During this period, journal entries were made with comments on research design, group dynamics, my ideas and developing conceptualizations about partnerships. After this workshop, I met with the representative of the partner organization to discuss my working relationship with her. Because she was not comfortable with being tape recorded, I made notes in my thesis journal describing highlights from our conversation.

Follow-up Data Analysis

A report that was descriptive of the content, process and outcomes of the workshop was prepared in collaboration with the representative of the partner organization. It was then distributed to the funder and each of the participants involved.

Researcher Roles

Multiple Roles

My primary role was that of researcher; however at times I acted as participant observer, workshop assistant, and occasionally I spoke of my experience with disability, disability organizations or partnerships that included people with disabilities. My connection to both the community of people with disabilities and a university research institution was explicitly
discussed with the partner organization through their representative and with participants of the workshops. After the workshops, I asked participants to comment on my roles and any confusion that may have arisen from them.

**Anticipated Benefits and Drawbacks of Consumer-Researcher Location**

Although previous investigations typically discuss the lived experience of "participants" rather than "researchers," within this study project, I assumed that my lived experience would also benefit the research: I had some insights into the organizational and access issues involved in planning the workshops and understood the terminology used by community members in the workshop and interviews. I was also familiar with some of the community-grounded philosophies, such as "Independent Living" and dilemmas such as "tokenism."

Fontana and Frey (1994) propose that having a strong rapport can assist the researcher to understand the issues from the perspective of the research participants and thus lead to more informed research. They also caution, however, about becoming the spokesperson for the group studied or becoming so involved that the role of academic researcher is abandoned altogether. These are some of the reasons why the research partner group was involved with the appropriate role of facilitating community action. I believed that community action was a critical component of the research. However, I did not view myself as being in the most appropriate position to take a sole leadership role in this area. My main agenda was to meet academic research criteria.
There was a significant shift in the roles I adopted for the third workshop in comparison with the first and second workshops. During the first two workshops I adopted largely a participant observer role, whereas, during the third workshop I played a direct role in planning, design, and co-facilitation, a significant turning point in the research.

In summary, the first and second workshops were analyzed to derive major themes from the lives of persons with disabilities and about their experiences in collaborative community partnerships. The third workshop was used to engage the ten individuals in exploring, elaborating and verifying these themes.

*Previous Work On Partnership: Community, Academic and Service Sectors*

While conducting the doctoral dissertation research, I continued to be involved in other activities. These activities that took place from the position of community, academic and service sectors, although distinct from the thesis study, also contributed indirectly to the shaping of my thinking about collaborative community partnerships.

I conducted an internship at the Hospital for Sick Children where I explored the use of a partnership approach to addressing the needs of children who received support from hospital staff, educational professionals, family members and community organizations. Within this setting, I was able to observe some of the challenges of building partnerships among professionals, as well as between professional and nonprofessional groups that shared the common goal of supporting an individual child. One of the challenges was to have parental expertise recognized (Krogh & Humphries, 1998).
At a community level, I was involved in two short-term contracts with Beyond Consulting Inc. (for a description of work, see Krogh, 1997; Phipps & Krogh, 1997). These contracts included: a) building community partnerships to support people with disabilities who want to become entrepreneurs; and b) community partnerships to address the needs of families that include children and adolescents who have Fetal Alcohol Syndrome. The contracts provided me with opportunities to observe the challenges and political struggles that exist among and within community groups. The importance of sharing a common set of guiding principles was highlighted through these experiences.

In terms of academic research, I was involved as a coordinator of a national research project on disability organizations in Canada. In particular, strategies that could support their ability to operate effectively in the present sociopolitical environment were examined. This project involved establishing a partnership among 3 universities, 1 university-affiliated disability research centre and approximately 25 disability organizations (Krogh, Boyce, La France, Enns, Kaufert, & Hall, 1998). As previously mentioned, one of the strategies that the community organization representatives discussed in this study was partnerships. Within this project we attempted to present the selection, use and modification of organizational strategies as context-dependent. Through interviews and group discussions, important insights were made into the present social, economic, and political pressures that led community organizations to consider strategies such as collaborative community partnerships. The process of negotiating and supporting such a large research partnership as
the foundation of this study provided me with insights related to the need for creating opportunities for building trust among stakeholder groups.

While conducting my MA thesis, a collaborative case study of a woman with a disability, I explored several elements of collaborative research partnerships. These included acknowledging expertise that is based on lived experience, ensuring benefits to her for her involvement in research, involving her in reviewing the data analysis for verification and dissemination of the results in lay public and academic forums (Krogh, 1993; Krogh & Lindsay, 1997).

In 1993 and 1994 I acted as a reviewer for an academic research fund established by the Social Sciences and Humanities Research Council of Canada in conjunction with Human Resources Development Canada. These experiences provided rich opportunities to discuss methodological issues related to collaboration among people with disabilities and academics from a wide variety of social science disciplines.

**Data Collection and Analysis**

*Interview Approach*

Semi-structured phenomenological interviews, as described by Seidman (1991), were designed to cover background information about the individual, concrete actions related to partnerships and thoughts, beliefs, and theories about collaborative community partnerships. By asking participants to describe themselves, I was able to use their own words to describe them as participants in the study. This is a critical concern within the disability community rooted in the history of their representation in research, and it has been described by researchers who work with other
groups of participants who have been historically silenced (Oliver, 1992; Woodill et al., 1992). The workshop experiences that I shared with participants were used in the interviews as a reference point to gently move the participant from describing common concrete experiences to more in-depth personal explanations and theories.

The approach taken in the interviews was heavily influenced by what Fontana and Frey (1994) call a gendered approach, developed in response to methodological and ethical concerns related to women's experience of being treated as objects in research (Oakley, 1981; Reinharz, 1992). This type of interviewing has also been described as an approach that treats the respondent as an equal and full person who is allowed to express emotions, resulting in a fuller representation of his or her view of the world (Deniels, 1983). Oakley argued that without reciprocity within the interview, one cannot have the intimacy that is sought in rich phenomenological interviews. With this approach, a researcher attempts to reduce traditional forms of hierarchy in interviewing. I did so in several ways: for example, I reassured participants that they could choose not to answer a question. On occasion I discussed my experiences with disability and partnerships when I thought it would put the respondent at ease or move the analysis of issues to a deeper level. In accordance with this approach, I allowed the participant to elaborate or "digress" from the interview agenda. Such strategies have been promoted by those using participatory and emancipatory research methods in studies involving people with disabilities (Vernon, 1997).
Thesis Journal

Journals were kept throughout the two-and-a-half-year thesis process. Within these journals I kept reflections about specific research activities. I also documented significant changes in my thinking about partnerships and the events outside of formal research activities of this study that also affected my thinking on partnerships. These journals included entries that were beyond the specific time frame and context of the central study activities. Documenting these reflections on events and changes in my thinking over time was considered important for increasing the dependability of the findings (see Mertens, 1998).

Addressing Bias in Research

I recognize that, in general, researchers influence or sometimes bias, the research they conduct and that they are influenced themselves by this research. There were several ways that I attempted to delimit and understand my influence upon the expressions of participant thinking and ensure that the ideas expressed by participants were grounded in their life experiences.

The issues explored in the third workshop were directly connected to themes expressed by participants during phases one and two and not merely my personal experiences. The activities were interactive, relying upon participant input rather than didactic lessons. The type of learning that took place involved participants in activities such as role play, mural making, discussions, exploring metaphors and individual story telling. In this way the participants were encouraged to learn from themselves and each other in a reflective and interactive manner rather than from me. The
workshop activities relied upon the participants to draw directly upon the partnership project they were involved with to illustrate their ideas. The participants were highly motivated to express and develop their understanding openly so that they could effectively apply what they learned to their partnership project in their home province.

The workshop was co-facilitated by a person with a disability who has an established role as an executive director of an organization run by a majority of people with disabilities. This structure influenced the way the project was presented to others, and was intended to prevent participants from developing the impression that I was “the expert.” It also reflected the shared belief that expertise can be based on lived experience.

The participants’ ideas were gathered in the study in a way that looked for consistency or development over time. Their ideas were obtained at different times, for example, through the pre and postworkshop interviews. They were also expressing their ideas over an intense four-day period and in a variety of modalities such as a written learner’s contract before the workshop and dramatic activities during the workshop. There was an opportunity to identify any significant inconsistencies in the ideas expressed and to have them documented in my thesis journal. There is further discussion, below, regarding triangulation of data.

*Cycles of Data Collection, Analysis, and Action*

Data collection, analysis and action within qualitative research is a cyclical or iterative process (Miles & Huberman, 1994). In addition to the immediate follow-up analysis of data collected in phases one and two, the data from all phases were analyzed collectively. The first and second phases
represented distinct cycles of information gathering, analysis and dissemination, and formed the foundation for the third phase.

The third phase was methodologically significant in terms of examining the theory generated and its broader applicability. Participants were encouraged to explore, debate, expand, confirm or disconfirm the importance of the central themes identified in the first two workshops. It was also a time to test the applicability of the developing theory and conceptual framework in a wide variety of collaborative community partnerships. Participants were supported in sharing what they already knew, identifying important issues related to partnerships, developing conceptual frameworks and explicating their implicit practice-based theories.

*Composite Data Analysis*

Data were analyzed using a qualitative thematic approach (Bogdan & Biklen, 1992; Lincoln & Guba, 1985; Miles & Huberman, 1994). After the phase one and two cycles were complete, including preliminary data analysis, the final composite analysis process began. Several data sets were integrated in the NUD*IST* qualitative data analysis computer program, including the summary reports of phases one and two, the pre and postinterviews for workshop three, and transcribed group discussions that took place during workshop three. These data were coded in a manner that led to the development of a hierarchical set of categories (nodes) and related subcategories (subnodes). These exemplars were then added to the computer nodes within NUD*IST* that were established through the analysis of the interview data. Finally, the five thesis journals were coded as off-line
documents, allowing themes or elements of the documents to be added to the hierarchical coding structure within NUD*IST without entering the entire text into the computer. Thus exemplar quotations representing significant themes from the journals were integrated with the elements of texts from other sources that represented similar ideas within a category. The process began with the interview data because it was seen as the rawest form of data that was most closely connected to participant beliefs. The group interaction was analyzed next as it represented theorizing that took place at the group level. Finally, the journals that represented some of the ongoing theorizing that I had been generating throughout the study, were analyzed.

**Applying Research Quality and Emancipation Criteria**

Criteria for testing the soundness of qualitative research must be considered when designing a study. This study was designed and implemented in a manner that reflects the theoretical principles of the methods drawn upon: participatory action research, critical pedagogy, grounded theory, and critical participatory ethnography. Below, the design features are described based on some of the criteria proposed by Mertens (1998) to assess qualitative research: credibility, authenticity, transferability, dependability, confirmability, catalytic validity (also see Lather, 1986a), and conscientization (also see Freire, 1993).

**Credibility**

There were several ways that credibility was addressed including: prolonged engagement in the community, member checks and triangulation.
At the beginning of the project, there were prolonged periods of time spent at the site of the research partner organization in order to become familiar with the context in which it was operating. During these site visits I lived with an active member of the community and disability advocate. I attended local functions and spent time in the organization’s office talking to staff, members and board members. During the first workshop, I spent a great deal of time keeping in touch with the people from the organization who were planning the workshop. I also attended one follow-up meeting and engaged in interviews. Through this experience I was able to learn more about the operation of the organization, the community context and the workshop goals. I spent time with the facilitators before and after the second workshop in order to better understand their goals, ideas and reflections. After this workshop I was able to spend time with several participants in a one-to-one telephone interview, group debriefing and informal discussions.

In preparation for the third workshop I was able to become increasingly familiar with the participants, their partnership project, views of partnerships and learning goals. In addition to the time spent directly on research activities, I also was involved in several community disability-related projects and disability organizations. These experiences allowed me to develop a rich sense of some of the relevant issues and events within the context of the disability movement in Canada.

From 1994 to 1996 I was involved in peer debriefing with a learning partner who was also working on her doctoral thesis. She and I discussed relevant issues and interviewed one another about the stage of development of our thesis projects. Within our discussions we talked about
methodology, theory, literature, findings, and conclusions. She had a background in critical theory within sociology which I found helpful because it challenged the traditional ideas about research that I had become exposed to in my previous training. My developing constructions related to partnership were documented through five thesis field-note journals. I also engaged in self-interviews during each of the three stages of research. These interviews were tape recorded, transcribed and added to the journal data set. This level of self-monitoring contributes to meeting what Mertens (1998) refers to as the criteria of progressive subjectivity.

Member checks, a process of confirming findings with representative members of the group being studied, were also used to increase the credibility of the data and analysis. The summary reports prepared after the first and second workshops were circulated for review by the organization representative and each of the participants involved. Modifications were made before the final version was printed and distributed. During the third workshop, the facilitators reviewed discussions or group notes in order to check that the proper meaning was being conveyed. The research partner representative was also involved in reviewing preliminary analysis summaries and the final contents of the thesis.

Efforts were made to triangulate the source and type of data collected. Information from participants in workshop three was gathered over a six-week period in a variety of formats including writing, talking, drawing, drama, paired discussion, small group discussions and large group discussions. This information was combined and compared with data from field notes in the thesis journals, interview data, participant observation
during the workshop, workshop flip chart notes, and participant documents such as the learner's contract.

**Transferability**

Within qualitative research, transferability can be supported through thick description. However, transferability requires the reader to determine the degree of similarity between his or her own situation and the context described in the study. The third phase, as previously discussed, provided a rich opportunity to test the applicability of the developing theories of partnership in a wide variety of collaborative community partnership settings across Canada.

**Dependability**

Within constructivist qualitative research, change over time is expected. This evolution in thinking should be carefully documented and others should be able to track the change over time through an inspection of the data documents used. Within this study, major changes in thinking are documented in the thesis journals.

**Confirmability**

This issue is concerned with tracking conclusions to data sources and describing clearly the logic used to interpret the data. An audit trail is used in the reporting of results in the following chapters and in identifying the direct sources of an idea or quotation. Each quotation used is followed by a code that indicates the phase of the study, whether it was a pre or postinterview, the speaker and the text unit(s). Citations from the thesis
journal may be used to identify the stage of concept development, thus providing what Miles and Huberman (1994) refer to as a “chain of evidence.”

**Authenticity**

Authenticity requires a balanced presentation of perspectives, values and beliefs (Stainback & Stainback, 1988). In this study, which focuses primarily on the experiences of people with disabilities, I recognized that people with disabilities do not form a homogeneous group. The acceptance of a variety of interpretations of inclusion in collaborative community partnerships ranging from validation to oppression is reflected in the central research question. The thesis attempts to describe and understand these different perspectives.

**Conscientization**

In an ideal study, the participants increase their consciousness of their experiences of the world (see Freire, 1993; Mertens, 1998). The workshop experiences provided people with an opportunity to have their perspectives heard and at times challenged by others. Phases one and two interviews provided an opportunity for participants to reflect upon their experience and their ideas about partnerships. In phase three, participants were invited to participate in an individual and group process of transformation. On an individual level, participants were asked to develop their own learning contract that was geared to what they wanted to learn and apply in their own setting. During the four-day workshop they participated in activities that led to further development of individual learning. In part this was achieved by having the participants share their
stories, allowing others to determine commonalities and differences among the settings. In the third phase, participants were also interviewed before and after the workshop, providing opportunities for reflection. Changes in the thinking of workshop participants were documented through postworkshop interviews, participant observation and the thesis journal.

**Catalytic Validity**

Given the Participatory Action Research influence in this project, this was a very important criterion to meet. Catalytic validity is the extent to which action is generated from the study process (Lather, 1986a). This form of validity was apparent in this study on many levels. For example, the research followed a naturally occurring community action in the form of workshops rather than generating an artificial experience to meet research purposes; practical assistance was provided to support the implementation of these workshops; and summary reports were provided and used by participants. Several participants from the first two workshops formed partnerships and worked together to bring about change. In the third workshop participants were supported in developing plans of action for their local communities. More work in this area was desired, however, the funder removed the “follow-up” phase of the project proposal, leaving us with limited financial resources to conduct national networking in support of local action. We kept in touch informally after the funded project period. A few participants from the third workshop have since contacted me or other participants to receive support with their partnership action plan.
Standpoint Epistemology

The criterion of standpoint epistemology highlights the importance of the researcher to acknowledge and describe his or her own standpoint and the context from which the research was generated. It questions notions of a universal truth since all knowledge is considered to be context based. Information about my position in relation to the research has been provided in Chapter 1 and in the present chapter. Information about the sociopolitical context of the study is provided in Chapter 2.

Reciprocity

To meet this criterion, the researcher is required to demonstrate that the study leads to the development of trust and mutuality between the researcher and the participants. There were many activities that were used to develop trust among the people involved in the study, including developing written partnership agreements. Within this study, the issue of trust was demonstrated in many ways. For example, the research partner organization and its representative felt that enough trust had been established between myself and them that they entered into another lengthy study with me.

Efforts were made to support the participants in benefiting from the research activities. In the first workshop my role, as guided by the research partner organization, included developing daily evaluation forms. This information was used by the facilitators to alter the workshop in response to the needs and concerns expressed through the forms. My role in the second phase involved providing general assistance with the organization of the workshop, such as identifying a free workshop site. As mentioned, in
the third phase, I fostered participants' development of relevant community action plans.

**Sharing the Perquisites of Privilege**

As part of this criterion, researchers should be prepared to share the benefits of research. Each of the three phases proceeded with a written partnership agreement in which benefits were outlined. At each phase of the study, the parameters of our working relationship were described, for example, the benefits that the partner organization would receive (see Krogh, 1996). In this manner benefits from participating in the research and the terms of participation were explicitly addressed.

**Summary**

In this chapter, I have described each of the three phases of research as well as the research site, my position as researcher, the data collection methods and the analysis procedures. As described, this study was conducted in a manner that maintained a connection to the community of people with disabilities through the establishment of a research partnership with a disability organization. This arrangement provided me with an opportunity to explore and address issues related to reciprocity during the study, something raised by disability theorists as important. I concluded the chapter with a review of the criteria for assessing both qualitative and emancipatory research, illustrating how these were taken into consideration during the implementation of this study.
CHAPTER 4
ATTITUDES AND VALUES THAT
AFFECT PARTICIPATION IN PARTNERSHIPS

Introduction

In this chapter I describe how people's attitudes, stereotypes and values appear to influence relationships within community partnerships. For example, according to the participants, people with disabilities are frequently expected to play a passive "disabled role" while many nondisabled people may see themselves in a "charitable caregiver role." Attitudes that emphasize disability rather than capability, and homogeneity rather than diversity among people with disabilities were often identified by the participants involved in this investigation as problematic. After describing attitudes that affect group dynamics, I present central values that create conflicts such as the role of emotion in communication, perspectives about time, source of expertise and forms of valuable contribution. Following this, I describe participants' experiences with tokenism as well as the importance they place on consumer control. Finally, I focus the discussion on social change and meaningful participation within partnerships. In this last section I cover the following topics: the challenge of personal change and influencing group dynamics, supporting meaningful participation, clarifying levels of involvement in partnership and considering contextual factors affecting the partnership.
Attitudes Toward People with Disabilities: Medical and Charity Models of Support

Individuals representing different partner groups bring unique attitudes to a partnership initiative. In this investigation I found that attitude was a critically important component of developing a working relationship in a partnership. As illustrated in the following quotation, without an open mind to challenge one's own attitudes affecting the full inclusion of people with disabilities, efforts such as building a wheelchair ramp will serve little purpose.

But I think it's inclusion and inclusion does not mean a ramp, it's about attitude first. You can have a ramp and the door [at the top] is closed...we have to open your mind first and after you put the ramp and it's okay - it's open, but if you put the ramp before and they're not ready to accept the other people with the difference [this is a problem]. ON-LINE DOCUMENT: Ph3D1 PAF*203.

What follows are attitudes that were perceived by participants to be held by nondisabled people.

A Focus on Disability Rather than Ability

Several participants who had disabilities spoke about how some people who represented other partner groups in a partnership focused on the disability rather than on the abilities.

[There is the] misconception that people with disabilities cannot do things. And of course it's also the misconception that because people are disabled, they are also, they don't have the mental capacity to do things. I believe that there is a focus more on disability than ability. ON-LINE DOCUMENT: Ph 3 Pre FABRICO*232.
The following excerpt from an interview conducted with a professional service provider illustrates a response consistent with a medical model of disability. When asked a general question about inclusion, she responded with a comment that emphasized the barriers or limitations presented by one participant’s disability.

Well I think that the lady that you’re mentioning right now was probably in a really good space, she was obviously well controlled on her medication; she was on a nice, even keel; there was no evidence to me of her long-term mental illness being very out of control that week. So I think we were very lucky. ON-LINE DOCUMENT: Ph 1 - Int KO*191.

This type of emphasis appeared not only to influence the way participants saw themselves and each other but also the roles they would assume or be expected to play within the group.

Expected Disabled and Caregiver Roles

Several consumers specifically discussed the “disabled role” that they felt that they were expected to play, that is to be a compliant and grateful recipient of assistance. The expected and actual roles clashed when people with disabilities used more direct or sometimes even aggressive methods to increase their voice within community partnerships. One participant stated,

As long as you’re meek and mild and do what you’re told and keep your place, they’re happy with you. But the moment you become independent and have your own opinion and start speaking up, they don’t like you so much. All of a sudden you’re a challenge to them. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*228-230.
As the following two excerpts from interviews illustrate, this disabled role not only reflects an image of a person with disabilities as a child in need of assistance, but also emphasizes the role of the nondisabled caregiver who knows what is best for others. The first comment was made by a person with a disability and the second was made by a person who has direct experience working in a service provider role.

It’s almost like [the way] some people treat children... as long as you keep your place, then you’re okay. But once you’ve reached that teenage stage where you’re trying to get your independence and all that...then some people tend to try to squash you further...other parents might let you grow. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*232.

Particularly with people with disabilities, the approach that we’ve taken as a society is that we have to take care of them. And we know best. And we’ve created all sorts of infrastructures that went along with the idea of how they should be taken care of ...they’ve certainly been a people that have been disempowered. ON-LINE DOCUMENT: Ph 3 Pre DIANNE203.

This type of approach affects people with disabilities personally when they feel that they are not consulted directly on matters that affect them. It also affects the working relationship within partnerships. One participant who has disabilities affecting learning and vision shared stories about being left out of discussions that related to her. She repeatedly expressed the frustration that she felt when people talked about her as if she were not in the room (ON-LINE DOCUMENT: Ph3 Post EMA*47).

Another participant spoke about how entering a partnership as a representative of people with disabilities can lead to similar patterns of patronization and dismissal. She believed that this reaction takes place
because of the inequity that exists at the time that the partners enter the partnership.

I think sometimes that patronization of what you're trying to present happens because the balance of power isn't there, because the equality isn't there... it's so easy to be patronized and kind of shoed out the door. **ON-LINE DOCUMENT: Ph3D4 CONFLICT**81.

Some people who are nondisabled view themselves as doers of good deeds toward people who have disabilities. According to several participants, the manner in which these people perceive themselves directly interferes with the collective work within partnership projects. This phenomenon is depicted in detail by one of the participants, below.

There's a lot of... gratuitous goodwill around disability...when somebody with a disability becomes involved as part of a partnership...a lot of patronizing and excessive concern and those kinds of things [occur]. And that's difficult sometimes to get over...I personally consider that that goodwill is a real barrier to the advancement of people with disabilities. I think it stops people too soon. They don't get to the real issues about equality and independence and decision making that you need to get to -- just because you run around feeling good -- because you've got all these good feelings....They don't ever see them [people with disabilities] as valuable contributors to the process...I mean the attitudinal barrier is a bigger one than access is, in my view...because the focus is on the disability and not on what somebody might be bringing to the table in terms of experience, in terms of knowledge, in terms of understanding about the impact that decisions will have on people with disabilities...Presumably they invite you or your organization or whoever, to participate in the partnership because they want the perspective of someone who has a disability, right? And then you're cut out because they can't get past this thing -- that image and self image that they have about what good people they are. But at the same time...I mean that goodwill is a resource...I mean it really is. But to get to a place of equality is really hard when those...
attitudinal things are so strong for folks. ON-LINE DOCUMENT: Ph 3 Pre INGRID*175 & 181-197 & 236.

This participant also acknowledged at the end of her comments that there may be some strength in an initial display of individual goodwill. However, she indicates that without efforts toward equalizing power among the partner groups, this goodwill can be damaging to the working relationship.

As described by one participant below, goodwill as part of the charity model has become institutionalized as a method of service provision. This form of charity has also had an impact upon individuals with disabilities:

The manager of one of the disabled group homes...they have a real problem with people doing too much for disabled people so that they don't learn to do what they can do for themselves -- [in order to develop] Independent living skills, so to speak. ON-LINE DOCUMENT: Ph 2 - Int SO*100.

This model may have a variety of detrimental impacts upon the full participation of people with disabilities in partnerships. One participant detailed several ways that a charity approach may influence the formation and implementation of a community partnership.

It was always an ongoing struggle to operate in that partnership from a stance of equity. There...was constantly attempts on the part of...the mainstream, able-bodied organization to take the fairly traditional role...when it came to being involved with an organization of people with disability...that was evidenced in everything from the way the initial contact was made and the expectations that you know [people with disabilities had limited capabilities] -- there was an able-bodied person present who would be able to speak to and organize whatever it was that we were interested in doing, to the exclusion of an organization of
people with disability in partnership activities that did not directly involve the theme of disability. So I think all of that affects one: the opportunity for people with a disability and/or organizations to be involved in partnership and then, two: influences the nature of the relationship because you're working to erode and mitigate for all that baggage. And I think that adds extra weight to the whole process. ON-LINE DOCUMENT: Ph 3 Pre HELEN*212-270.

This participant went on to explain one of the reasons why she felt that change was so difficult.

What is it -- over five hundred years of colonialisit imperialist historical tradition. And our institutions are based on those traditions. So it's not going to go away overnight. ON-LINE DOCUMENT: Ph 3 Pre HELEN*271.

Several participants were favorably disposed toward an alternative, Independent Living Model of service delivery that utilizes consumer expertise based on lived experience, for example, through peer support.

**Attitudes of People with Disabilities toward Themselves and Others: Recognizing Capacities and Heterogeneity**

The participants involved in this investigation identified several attitudes that they perceived people with disabilities to hold. As explained, some of these have developed or become strengthened as a result of their interaction with people who hold different beliefs.

**Emphasis that People with Disabilities Place on their Capabilities**

People with disabilities involved in this study frequently emphasized their capabilities when describing others' contrasting perception of their
limitations. Many of the participants spoke of their capabilities as individuals and as contributors to a community partnership.

I can do everyday things. People think that I can't -- Like for example, cleaning house and stuff like that, you know, and being out on my own and doing recreation, like going out to anything that you would go to. It's just that, like I said, I need tools to get there and to go do it. ON-LINE DOCUMENT: Ph 3 Pre EMA*84.

Maybe we seemed pretty egotistical here, but we feel that people with disabilities, we feel that we know how to make things work. We know what it really means to collaborate with people, to sit down at the table. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*281.

**Heterogeneity within the Disability Community**

Several of the participants interviewed pointed out that although stereotypes of people with disabilities assume common characteristics among all people, there were in reality great differences among individuals. (As will be discussed in Chapter 5, heterogeneity within a partner group has implications for representation responsibilities.)

You can't assume that all consumers [people with disabilities] are going to see things from the same point of view... you know, that's stereotyping...Some of us are pretty ugly and abrupt, just like able-bodied people, we come in all different shapes and sizes. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*457 & 257.

Linked with the stereotypical image of homogeneity is the dubious assumption of the static nature of disability. The definition of disability itself is brought into question when people experience, for example, shifts in physical states such as acquiring a disability, recovering from a chronic illness or experiencing a remission from symptoms. These physical changes
may be accompanied by a psychological shift in the way people view
themselves and their use of the “disabled” label. What follows is an entry in
my journal when I was making a shift psychologically to match the
improvement in my physical state. This shift was done in a manner that
acknowledged and honored my direct experience of living with a disability.

If my health is affected again, I'll have to do it all over again [change identity from
nondisabled to disabled]. Interestingly, the psychological [identity] transfer is much slower
and more difficult than the physical. I am the sum of my experiences - I will always be an
advocate for people with disabilities -- but don't try to categorize me! ON-LINE DOCUMENT:
Journal#2. p.100

Attitudes of People with Disabilities toward Others

As discussed above, attitudes may negatively affect interpersonal
interaction. These harmful attitudes, as described by participants, can be held by anyone, nondisabled or disabled. One participant stated, “That’s conditioning. And the conditioning is on both sides of the fence” (ON-LINE DOCUMENT: Ph3 Post
INGRID*240).

One participant explained how people with disabilities should examine their attitudes toward people who are nondisabled. She also referred to a situation in a partnership where the need of people with disabilities to acknowledge and address power issues was not understood by others within a personal, historical, and sociopolitical context.

We can get into the rut of treating all able-bodied people like they're controlling monsters. You have to realize that there are some very beautiful and understanding people out there that don't treat you in a condescending way. They treat you... actually see you as an equal even though you have a disability. And they wonder what all the fuss is about...he doesn’t always understand that we’ve developed attitudes towards able-bodied people, so to speak,
because of the way we have been treated. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*324 & 302.

Value Conflicts Affecting Partnerships

Several values held by nondisabled and disabled persons appear to be in conflict, according to the participants involved in this study. Differences were not always clearly delineated according to disability or professional status. In some cases, this conflict is experienced at a personal level as people struggle to do either what they themselves see as appropriate or what they know others will see as appropriate. These conflicting values may interfere with communication and the negotiation processes involved in community partnerships.

The Role of Emotion in Communication

Throughout the three phases of the research, issues related to the role of emotion in communication arose. In the first workshop, during which time interpersonal issues were explored, the issue of emotional expression became apparent. The comment below was made by a service provider and introduces the contradiction between not wanting to show emotions and wanting to be seen as human by those who receive her services.

KO I think the professional is probably far less vulnerable than the consumer in this case. The professionals are trained to keep their emotions under control and at bay, and you don’t rant and rave and carry on, it isn’t professional, stiff upper lip, British stuff, not quite, but if you’re going to be professional -- you retain a professional approach throughout the whole business. The lay people may not have the same coping mechanisms that the professional does and a lot of them have been told that it’s all
right to let it all hang out and to let their emotions flow free and so I think there is a difference between professionalism and layism.

KK And yet, there's a dichotomy there because you were saying [earlier in the interview] that it is important for them to see you as a human being and part of seeing you as a human being is seeing the emotional side of you. Right?

KO Yes. But there and again, to see the emotional side of me. They are only going to see the emotional side that I choose to let them see. It would be very, very out of character for me and probably a few of my professional friends to let it all hang out in a [working] group. ON-LINE DOCUMENT: Ph 1 - Int KO*195-201.

A person with a disability from the same workshop referred to the expression of emotion by professional service providers. She proposed that expressing emotion can improve the quality of service.

I think they're mostly taught to be stand-offish. It's for them to do that - not to get caught up, not to get emotionally involved. And I think it's to their detriment that they are not emotionally involved, because if they were more emotionally involved probably they would do better work. ON-LINE DOCUMENT: Ph 1 - Int OO*692-694.

A third participant from the same workshop who recently immigrated to Canada from the Philippines discussed emotions as necessary for understanding others and building community.

Feel. The way others feel. Imagine ourselves in the shoes of others. That's what it's all about. If you are talking about community, that is what my understanding is. ON-LINE DOCUMENT: Ph 1 Report*196.

The quotation above illustrates that participants perceive others' emotional expression or lack thereof as inappropriate or appropriate. As my observations and interviews from the workshops attested, these differences
appeared to affect group dynamics and might therefore also affect the interactions within a variety of community partnerships. The organizers' values concerning the role of emotion were reflected in the activities. For example, some believed that role play that included emotional expression was an important part of the workshop. The following excerpt from my journal details the challenge of dealing with different approaches among several planners:

J said that it's more of a soul thing - it's more of a heart thing [for her], and she finds that R comes in [to the room] in a head state, and wants to do things 'boom, boom, boom.'

The implications of expressing emotions within a partnership were discussed in detail by participants involved in the third workshop. One large group discussion explored many facets of the issue; for instance, the misunderstanding and lack of credibility associated with expressing emotions which, in turn, appears to lead to a reluctance to show emotions on the part of some people with disabilities. They discussed the dilemma of also wanting to be able to present themselves and their issues in a holistic manner.

P1 And of course I'm glad I'm not the only one who gets emotional here but sometimes when we get emotional, they put more pity [on us] -- oh she's got a disability, she doesn't know how to get emotional or she wants more pity. And so people with disabilities, they kind of hide their emotion because they don't want more pity.

P2 They use it, it's like she's a woman or she's too emotional or she's disabled or, you can find all kinds of reasons [to diminish the validity of the contribution], and that's unfortunate because although the factual stuff is important, the emotional part is
also important as well...we almost have to shut that emotional piece down - so you’re not really coming at it from a holistic perspective.

It’s a hard issue. I think you want to be real, you don’t want to lose that human part of you and yet if you become emotional, people find all kinds of reasons to not listen or not respect what you’re thinking or feeling. ON-LINE DOCUMENT: Ph3D4 CONFLICT*138-144.

Although they indicated a reluctance to express emotion, a few participants also discussed the value and effectiveness of using one’s emotions to convey the importance of an issue.

Sometimes it’s a very effective tool. You’re so committed to what you’re saying that you are very emotional but it’s a very controlled emotion and what it does is it just comes out as a strong emphasis because many of the issues that we deal with are emotional and you can’t separate yourself from that, but as long as it’s a controlled emotion so that it really emphasizes the point. ON-LINE DOCUMENT: Ph3D4 CONFLICT*146.

It appears from these interviews that several participants thought that the expression of emotion was acceptable only when it is highly controlled.

**Perspectives about Time**

Differing views about time appear to have a significant influence upon the people who are working together in a partnership. As illustrated below, some people equated doing things in a short period of time with efficiency and fiscal responsibility. Meeting these criteria may legitimate placing limits on the full participation of people with disabilities in a partnership.
We have to be fiscally responsible, we have to be inclusive, but we've also got to be realistic that there are time-lines, there is definitely fiscal restraint, none of us can deny that... guardianship is such a huge subject involving such a wide range of people in the community but I don't know that we could ever have a totally representative workshop. ON-LINE DOCUMENT: Ph 1 Report*239-242.

A different approach to time is seen as necessary, given the practical issues involved in partnerships that include people with disabilities who may require access accommodations such as alternative format communication, like sign language or the production of information in braille or large print. One participant described how, because of her disabilities, time issues directly interfered with her ability to participate in community partnerships.

There was one time I felt really uncomfortable because I was trying to ask questions and it was just rush, rush, rush. ON-LINE DOCUMENT: Ph 3 Pre EMA*124.

Well that's what they say. They say we don't have the time and we'll need to pay someone else to do that [provide access accommodations such as whisper translation] and... ON-LINE DOCUMENT: Ph 3 Pre EMA*191.

Sometimes it can be hard for a person with disability to be in a partnership because I sometimes, in a long session, it might be too long for them and they can get quite tired because I know some of our members, if we meet more than two hours...I mean the third hour it's not going to make sense and they're not going to be able to function and to participate in the meeting, so sometimes there needs to be breaks. ON-LINE DOCUMENT: Ph 3 Pre EMA*217-219.

Several participants with disabilities emphasized the need to set aside ample time in order to build the relationship as a foundation for the
partnership work. One participant stated, "It always takes longer. Quadruple the time [expected], don't just double it. Quadruple it." (ON-LINE DOCUMENT: Ph 3 Pre INGRID*93) and another participant said, "Sometimes I think we have to take the time to do a partnership" (ON-LINE DOCUMENT: Ph3 Post BETTY*140). In the following quotation from an exploratory discussion that I had with one of the organizers of a workshop, I reflected on the time it takes to build a partnership.

I see the benefit of people coming together when they share past experience, understanding and values but I see a lot of potential if people who have very different positions come together too -- [but] it certainly isn't efficient -- I means it's the last thing that some of these diverse -- really diverse partnerships are -- it's not quick and easy and you get your stuff done -- it's like a long process of trying to see the other person's perspective and first of all just trying to make yourself open to listening to another person's perspective. ON-LINE DOCUMENT: Ph 2 - Int PO*301.

The idea of patience was discussed by several participants; they described the goal of having people learn how to support the participation of others and create a new process where everyone is heard. One said,

Partnerhip needs to have enough time to find new ways to work together. So there was [in the role play scenario] some feeling that there wasn't enough time spent on preparing the Minister on how to communicate with Heather [an individual with a disability who requires support in communication]. [We must] be patient and gentle with ourselves, that this is ongoing work that's happening and that sometimes we do get a bit impatient with the process. ON-LINE DOCUMENT: Ph3D4 CONFLICT*31.

Finally, several participants spoke specifically about how social change itself takes time and requires patience.
Because we don't exactly know where social change actually takes place...it's not overnight and it takes a lot of people to make change. It takes a slow erosion of able-bodied thinking to create change for people with disabilities. ON-LINE DOCUMENT: Ph3DY 4 CONTRA/REP*187.

I think in terms of our own practice as people in the community working with other people, mobilizing other people, we need to keep this in mind, the fact that it takes a lot of time and a lot of hard work to bring about social change. ON-LINE DOCUMENT: Ph3DY 4 CONTRA/REP*195.

**Appreciating Different Forms of Contribution**

As part of an ideal vision of partnership, one participant recounted the interdependent community in which he grew up.

We were very interdependent in the community...we needed each other to exist. So that a person might be really good at fishing and another guy good at farming and a good guy at carpentry...They would share the skills. The carpenter would come over and build a piece on my dad's house, and my dad would give him a couple of fish that he'd caught. ON-LINE DOCUMENT:Ph 3 Pre GERALD*189-196.

Another participant emphasized the importance of recognizing contributions made, regardless of form. This notion is relevant to partnership work since, for example, one partner group may make a certain kind of contribution because it is consistent with their organization's mandate or their available resources.

I think that we have to give credit to everyone that participates in social change, instead of thinking that we're the only ones that are actually doing something. Because everybody feels like they're doing something. They might not be working on the same issue as you are, or in the same way you would or with the same people that you would...And their
contribution to that same issue might look different. They may want to contribute something different, they may be able to contribute something different. ON-LINE DOCUMENT: Ph3DY 4 CONTRA/REP*189-191.

Within many disability organizations, such as Independent Living Centres, valuing expertise that is based on lived experience is often emphasized. This idea does not fit within the more traditional model that portrays the trained service provider as an expert in the needs of people with disabilities. At one point in this study, I came face to face with how strong my beliefs were; beliefs that may have been deeply rooted from my years of work in the community using the Independent Living Philosophy.

In a meeting among the organizers of a workshop, one person emphasized the extent of his facilitation expertise that developed as a result of his training. He then stated that another organizer who had experience living with disability and organizing community initiatives, really required more academic training in facilitation. He framed his comment to suggest that this judgment was a realization that she came to after speaking to me, implying that I shared her views on expertise! I exploded inside. I wrote in my journal, "Well, I didn't like that, because it put it on me - that I actually gave her those impressions! I didn't actually like to hear that [this person] had all those courses and training. I really responded to that" (ON-LINE DOCUMENT: Ph 1 - Self Int* 26-29).

People with disabilities in this study shared positive and negative stories about having different forms of contribution and expertise acknowledged. One participant who represented a disability organization detailed her experience of working in a partnership to build an apartment building with wheelchair accessible units.
All forms of contribution were considered important, not just the contribution of money. And those were the things that conflicted most often. The people who were going to be users and beneficiaries of the building had really strong views about it, and the people who were providing the resources had strong views on the other side. So it was an exercise in consensus building to get the thing up! Not just the apartment building...that was very profound in terms of my understanding that everybody's voice has equal weight if it's going to be a true partnership. That perspective and experience count as much as dollars. ONLINE DOCUMENT: Ph 3 Pre INGRID*78-81.

Another participant depicted her experience of not being seen as a valuable contributor to the community project initiated in the first workshop included in this study. This feeling arose when the participants held a follow-up meeting one week after the four-day workshop experience that had been designed to foster a community partnership. At this meeting a few people, primarily those who were service providers, had proposed that they form a core group to take on the major responsibilities of the project. This participant had presented a metaphor to the group: the earth was going to be destroyed and there was one spaceship for survivors with limited space; a decision was required about who would be on the ship. People in the meeting room showed no indication that they understood the point that she was trying to make nor did they ask her to explain why she was telling this story. Her views as well as her experiences of being disregarded became clear in the follow-up interview. She recounted,

...he was saying about only a few people to be there, well I said if I am not that important, I might as well [hand gesture indicating 'drop out'], that's why I...said about that story in that spaceship. But I know that I have the right to preserve my life but if there are people who are needed more like a baby about to be born, well I might as well give him the opportunity to be born on this earth than me, if I am older, you know... It's very precious [the
contribution of persons with disabilities, including those with severe disabilities] because you never know these people and what they know because of what they are and their experiences are just precious to put in together and understand better, and I don't know when X said that. Oh my God! Sometimes I don't feel that way...confrontation - I [felt it was] better to say it first [step down from group] before I will be [hand gesture indicating 'asked to leave'] ON-LINE DOCUMENT: Ph 1 - Int MO* 181-219.

This example illustrates how some people's contributions are ignored by others.

**Tokenism and Consumer Control**

Tokenism is another factor that can affect both the organization of a community partnership and the interactions that take place within it. Consumer control is a concept that has strong personal and historical roots for people with disabilities. Some participants have worked diligently to find ways to integrate this element into the community partnerships in which they participate.

**Images of Tokenism**

When participants in the third workshop were asked to draw a mural to represent the most pressing questions they had about partnerships, several participants drew pictures that represented issues related to tokenism. The example given below documents one participant's experience of being invited to be part of a partnership but not being provided with the supports to make her inclusion meaningful.

P1 Yeah, we had a project with [an organization] and what happened is we were in partnership but we didn't really have a chance to give our opinions or to really express
ourselves because, apparently because we had disabilities, they thought that our ideas were not good enough and that we...so we were more or less like, here's a door [pointing to mural], we'll put you in but you can't get out and that's why I put a person in the door so the person doesn't have the key so the person cannot get out and that's why, of my experience with working in partnership is like we'll sit [own name] here and we'll leave her there and she'll have to get back the best way she can [referring to her need for mobility assistance for getting from the meeting back to her hotel room].

P2 Can I just say something here? I think what we were getting at though is that's just one example of how she was not respected and not included in the process and how she was treated as a token member of this committee... She was invited to be there and invited to participate, but not supported to fully participate. One of the words that she used was mascot. ON-LINE DOCUMENT: Mural*48-49.

As one participant who has experience with partnerships that involve research, put it, "They want to include you because they want to use you to get money to study you." (ON-LINE DOCUMENT: Ph3 Post GERALD*199)

Participants had vivid experiences of being a token person with a disability in situations controlled by nondisabled professionals. They shared their images. However, through discussion, interview and observation it became clear that others such as disability organizations, group facilitators, and government policy makers also play a significant role in reinforcing or challenging tokenism.

One participant narrated a dilemma that she faced as a woman who operated a cross-disability advocacy organization. She had been requested to send someone with a visible physical disability to a protest where the media would be present. Although, on principle, she totally disagreed with this approach and refused to participate, she stated in her interview that she recognized that even she, as a woman with an invisible disability had
on occasion sought to use representatives with visible disabilities, thus reinforcing media stereotypes.

Another participant spoke about how she believed that her participation and that of several other people with disabilities was a "feather in the cap" of a person involved in locating participants for one of the workshops. This participant described below how certain techniques, such as using guilt to coerce people with disabilities into participating, made her uncomfortable.

Yeah... it was very important to her, to have quote-unquote, the people that were needed to be there and act out that way...it was like we were very important there because we were kind of token people. We were token people from that group...which I understood and I thought that was ok, um, I was a little nervous about going in to the group, but I realize that B [another person with a disability] was a big key. Like she really wanted B to be there. And there was a time on Wednesday I guess when I... had gone but then you guys went an hour later and [I] didn't know about it... She [one of the organizers] phoned and she sort of said, "Well, B is here." Like knowing that, you know, B had said that she wanted to come back and talk to me. I just said, no!...that was kind of a trip...I gotta see what role she's coming from...I guess it was so important for her...it seemed in a way like it was a feather in her cap.  

In addition, participants discussed government policy as a potentially influential mechanism for supporting the inclusion of people with disabilities and the organizations that represent their interests in partnership projects. One participant spoke of policy that might make it necessary to have consumer representation as a condition for receiving government funding for the project or service agency:
Yeah, and it's not always easy. Mind you, government can make that transition easier, you know. by, you know, if they earmark funds for consumer controlled organizations, you know. Then these [service] organizations have to start thinking, well, maybe we have to put more disabled persons on our boards. Instead of having ten people who are able bodied on their board overseeing all the people with disabilities, then well, maybe we have to put some of these people on our board and get them making some decisions. And especially if they want to access funding. Now, at first it might just be tokenism. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*170-174.

This quotation indicates that meaningful participation requires more than just the presence of people with disabilities.

**Consumer Control in Partnerships**

Consumer control, which was discussed by many participants, is a crucial concept that represents an attempt to (re)claim the power lost in traditional social relations and therefore it is another way of combating tokenism. The term consumer is applied to people who receive special services. It is used to portray people with disabilities as people who should have some say in the type of services they obtain; they should not be viewed as passive recipients of charity. Consumer control, from both a personal and political perspective, is described in the following dialogue.

KK You've talked a couple of times about consumers and consumer control...and I'm wondering if we could explore that a bit...Why is it that consumers want to be in control?

J Basically, because for so many years doctors, parents, everybody made -- we had workers, teachers, professionals, they all made decisions for people with disabilities and lots of times, they were the wrong decisions and they weren't decisions that actually helped persons with disabilities grow and become independent. So the
consumer movement believes that disabled people know what is best for themselves and that they should represent themselves and so if you're trying to resolve an issue for a person with a disability, say recreation, it's not the recreation director... that actually knows what kind of fun we can have or want... it's more important for our opinions to be heard than theirs to be worked around. I feel it's us that should make the decisions [about] what services [there are] and that. In the same way, if you want health care services, you should be able to decide what doctor you go to and what hospital you go to and who looks after you. Persons with disabilities should have some say in what kind of transportation system is in the city and what kind of accessible recreation. ON-LINE DOCUMENT: JOANNE*125-129.

This same participant illustrated issues of control in a personal story in which she depicted her experience as a woman with a physical disability in a rehabilitation centre after knee surgery. As she spoke about the experience, I perceived that her lack of control was unbearable for her:

The physiotherapist would come in in the morning and put me on this machine for two hours, bending my knee, and then drag me out of bed and get me up to walk, put me in the chair for my lunch, come back after lunch, put me on this machine for two more hours, get me up, drag me across the floor to walk, they did that the first day. The second day, I was so totally exhausted, I said to them, hold on, I'm not a normal person. I can't do all of that. I said you've got to choose, either you want me on the machine or you want me to walk, I said I cannot do both of them twice a day. But I had to do that [speak out]. And then they were insisting that I sit with my legs flat and certain things, and to me that was very painful because my leg had never laid flat, it always had a little bend in it, and I tried to explain that to them and they wouldn't listen, they would take my pillows away from me and everything. ON-LINE DOCUMENT: Ph3 Post JOANNE*239.

She was only able to get her point across after she threatened to leave the institution by actually dragging herself down several flights of stairs.
while staff pleaded with her to stay. She also had a friend call to complain to the hospital administrator. After she demanded more control over her own care, her experience changed.

The next day they came in, some of them stayed away from my room altogether, because they were afraid of me after that, and when they came in, there was a whole different attitude -- what would you like, where would you like it, how would you like it? And that's how it should have been. ON-LINE DOCUMENT: Ph3 Post JOANNE* 239.

According to several of the participants who were interviewed, the difficulties that people with disabilities experienced in trying to have their voices heard frequently affected their decision to continue being involved in a partnership or their choice to join one in the future. In an attempt to be heard, some organizations have explored different ways of establishing a level of consumer control.

It can be hard in a partnership to keep consumer focus because often if you have like four corporations or government officials, bureaucrats or whatever, on the committee and only three people with disabilities, sometimes they can forget that it's [lives of] people with disabilities...that it's going to affect. And they run away with it and change the whole focus and so we like to keep it focused in a way that people with disabilities will benefit the most. And we feel that people with disabilities are the ones that can decide that. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*121-124.

Consumer control, as represented by mechanisms for ensuring that a consumer voice is heard among the others, was a characteristic associated with partnerships that the participants considered to be successful. The
following quotation details a unique and effective arrangement used to ensure consumer voice:

UO This partnership committee that we're in is working well... It doesn't have a whole lot of problems...[in comparison to other partnership experiences]

KK I wonder why that is...

UO Maybe because it was initiated by disabled persons. And maybe because their understanding when they first came on was that major decisions had to go before the board [of directors of a consumer-controlled disability organization]...So in the end it may have been a partnership but, if they [the organization] did not like something that was decided, they thought was controversial to persons with disabilities, then they could decide not to follow through. They'd tell the committee to go back and rework it, to do something different. So even though some of our partners may have the funds, and that does give them certain clout especially when you're trying to fulfil their criteria, if there's something in there that's really adverse to us, then we can veto [it].

ON-LINE DOCUMENT: Ph 3 Pre JOANNE*426-433.

**Barriers to Successful Partnership Relationships**

Participants in this study indicated that partnerships frequently require support in one form or another. It became evident in this study that people unconsciously or consciously replicate power structures within the context of the partnership even though there may be some level of belief that there is greater equality and power sharing than in the broader societal context. It was also evident in this study that resistance to change occurred at many sites including personal, interpersonal, organization, social movement, and partner group.
Ability to Relate to One Another

People were seen to be understanding of others' perspectives to varying degrees. One participant articulated this in the following dialogue:

OO  I think the differences were the different viewpoints that came across. The people who were the different care givers had a different point from people that were consumers. Um...and I saw that very distinctly. There was a big difference in the viewpoints and the attitudes. Between care givers and professionals and the consumers.

KK  Could you talk about that a bit?

OO  Well I think the care givers [providing hands-on direct care] in some respects looked at things with kind of a big picture and they were concerned about the people and the legislation, but I don't think they could quite relate to what it would be like if someone had that kind of power over them. Where the people that were consumers, seemed to be able to identify more with that power, and people having the right to say what was going to happen.

KK  And the service providers?

OO  The service providers were able to relate to some extent, but not fully, I felt the professionals were not really able. They were able to relate, because they wanted to relate, but it seems that often in discussions that I was in with people, that they just didn't quite understand what it would be like to have that right taken away. So there was a little bit of a difference there.

Power Positions Reinforced

Some participants viewed others within a partnership in the same way as they would within their roles in the social service system. One participant, involved in the first workshop who worked as a service provider and administrator described the way she viewed people with disabilities as follows:
It didn't take me more than a couple of minutes to have somebody sized up...because it's what I do for a living. It doesn't take me very long to have...their attitude or their whatever towards me ascertained very quickly because it's kind of my work. ON-LINE DOCUMENT: Ph 1 - Int KO*179.

On a larger scale, several service providers who participated in this workshop proposed that they form a small core working group to carry on the work of the partnership group. As an observer of this process I was surprised at how quickly people appeared to revert to their expected societal roles as leaders and followers. During the partnership workshop the previous week, participants had the support of facilitators to guide their thinking and actions, but once the facilitators stepped back, people appeared to play the dominant social roles that they were most familiar with rather than continuing to create new ways of relating and working together. I discussed this process in the Community Report for the first workshop.

I observed change in individual workshop participants over the course of the week during the workshop. People were making an effort to understand one another and to recognize inclusion issues for group members, such as reducing the cognitive complexity and level of abstraction, using concrete examples and reducing the use of jargon. However, the lasting effects of these group dynamics came into question at a meeting that took place during the week following the workshop. Several participants expressed during individual interviews, that they were uncomfortable with the direction the group was taking and saw it as becoming a more exclusive, professional-driven process. My observations of this situation led me to explore possible explanations. Central issues included the resilience of power positions within our society, cultural differences particularly in the manner in which information is presented and taken up, impact of personality differences on a group, and differences in terms of the external pressures that may have been imposed on some
participants to show concrete products, such as reports, in order to justify their participation to superiors and colleagues. ON-LINE DOCUMENT: Ph 1 Report*171-173.

One participant who felt disempowered by the experience described above, discussed her approach to participation in partnerships in a follow-up interview. She emphasizes the importance of being seen as a useful contributor.

But if I, if they don’t need me, well and good, but if they do need me I can put in more on my way of feeling about things and my experiences if they will just only pick the most important people it’s fine for me...[I want to be] where I can be functional. For what will be there? If I will just sit there and stare and wait...segregated...[facial expression and shaking of her head indicated “then I’m not interested in being there”]...But I don’t know why it switched entirely and make everybody feel like a stranger...Yes. It’s segregation...maybe one dominates, monopolize the whole [group] and I said [to myself] I don’t want dictatorship. I don’t want a dictator, no, no. ON-LINE DOCUMENT: Ph 1 - Int MO*203-251.

Her response at the time of the meeting and those of many of the people with disabilities in the room appeared to be consistent with the passive role that they were expected by others to play.

At the time of this follow-up meeting after the first workshop, I perceived that the facilitators of the group faced a challenge regarding their role.

I recognized a dilemma for the facilitators, wanting to step back to let the group take over the process and make decisions, however, there appeared to be a small number of people who felt very comfortable steering the group in a particular direction while others felt left out. While facilitation could be gradually reduced over time, it appears that the group could
have used more support in their efforts of self-reflection regarding group dynamics and linking group process to quality and objectives of outcome...it appears that such work would continue to require direct support of facilitators to monitor and support equality among all diverse partners represented in the project. ON-LINE DOCUMENT: Ph 1 Report*259 & 274.

**Personal and Political Resistance**

*Levels of Resistance*

The following comment was made by a woman who grew up in a rural area and later moved to an urban centre. It illustrates that resistance can take place at a personal level.

In a rural community often people are very much set in their ways, and they don't want to try, um, new things...they prefer to...just keep things the way they are, the status quo I guess. ON-LINE DOCUMENT: Ph 2 - Int QO*165-199.

When one of the participants of the first workshop felt uncomfortable participating in a group, she decided to limit her involvement, demonstrating resistance at an interpersonal level. Below, I explore this event in a self-interview the next day.

Yesterday, she was saying that she...was overloaded with the group - it was just too much for her. And she said...she felt that Q forced her and she hated it. She doesn't like to be forced to do something and she said she's told Q she didn't want to do the workshop any more. ON-LINE DOCUMENT: Ph 1 - Self Int*124.

This example illustrates that resistance in the form of challenging other people's expectations can be a form of personal empowerment.
A couple of examples of resistance at the organization and social movement level were described by participants.

A paper was written looking at how Independent Living Centres are meeting women's needs...it was a pretty challenging paper, and ah, not much has happened with it. ON-LINE DOCUMENT: Ph 2 Report*140.

But I think if, in my opinion, the Independent Living Movement is going to grow and develop, I think there has to be some change. Do you know what I mean? I think change is healthy. Change means development, that means growth and we have to start, you know...stop being so purist for heaven's sake. ON-LINE DOCUMENT: Ph 2 - Int RO*139.

The last quotation indicates an interest in resisting dogmatic forces within a movement.

Finally, one participant described the resistance that she experienced within a community partnership.

After I called her, I sent a fax. No answer, no answer. I said, "why?" I have an idea about that -- but to say nothing is a form of resistance. I don't know why she has resistance. I called her and [they said] "yes she is here, one minute." [I gave] my name, "oh she is very busy." It's the worst resistance when they say nothing. No words, no news, nothing. ON-LINE DOCUMENT: Ph3 Post BETTY*82-112.

Addressing Resistance Issues

This same participant described how she believed that it was important to take the time to understand resistance and the link between resistance and having limited information.
You have to sit down, take your time, don't try to bring the people on [your] side. convince -- you have to understand that they have resistance, the fear they have, and understand why. Because some people show many things but behind that...there's a kind of resistance, they don't show you the truth...All things arrive in good time...One day I think we will be face to face and the resistance will fall down. [It existed] because she didn't know me. ON-LINE DOCUMENT: Ph3 Post BETTY*86.

The importance of recognizing a link between resistance and other issues of conflict between members of a partnership was also described in the following quotation.

I have to work on the resistance because when we try to build a partnership, we encounter, we meet some resistance and sometimes we lose our partnership. The partnership is unsuccessful because we didn’t see the resistance. We don't look at the resistance, we don't understand. And I think many conflict situations come from resistance. ON-LINE DOCUMENT: Ph3 Post BETTY*102-103.

Another participant discussed how unresolved issues can become worse over time.

There are a lot of unresolved and fairly negative feelings...which in my opinion then feeds back into racism and ablism and homophobia and sexism you know, it tends to be, you know. "Why are we being forced to have a relationship with people?" And so I think I've seen... unfortunately I've seen a backlash of the whole notion of collaboration and partnership. ON-LINE DOCUMENT: Ph 3 Pre HELEN*380.

The previous comments illustrate that resistance may be grounded in fear, lack of information, racism or ablism and may affect people on an individual or collective level. This last quote, indicates that when issues of
conflict are unresolved within community partnerships, a general reluctance to participate may develop.

**Meaningful Participation in Partnerships**

Some people with disabilities have made an effort to distinguish between meaningful participation in a partnership from other forms of participation such as those that involve tokenism. Meaningful participation appears to require an examination of issues related to power and efforts to bring about change at a personal, group and community level.

**Challenge of Personal Change**

Changing the positions of power that people hold within society was experienced as very challenging. One participant disclosed that she really thought that there had been no real change with respect to power sharing as a result of a four-day partnership-building workshop:

OO But I even felt at the end of the week that the lines had been drawn. Kind of like "this is where you are and this is where we are" and you know, well for me it was pretty obvious.

KK Can you give me an example of like an activity or something that was said or something that can help me to understand...

OO Well there was, um a group of us sitting there and we were talking about some of the people that have come, and one of the comments made was that, "Oh they have come a long way, they have done very well," and it was very patronizing and it was like, I was thinking "Geez I wonder what they say when I leave?" And it was just, like, I just, I was thinking like "What's going on here?" you know, I'm thinking...but then I thought that's who they are, and you have to be...oh yeah, I should have been a real radical and I could have just said something and caused a big stir, and a big kerfuffle or said
"hey, you sound very patronizing," but I didn't think that would accomplish anything. I didn't think it would. ON-LINE DOCUMENT: Ph 1 - Int OO*583-599.

In order for personal change to take place, people must work to see other people's perspectives. One participant spoke about how she could relate to some of the perspectives that nondisabled people held because she herself was able-bodied before she acquired a mental health disability. She also spoke of how some of the nondisabled people with whom she interacted assumed that they could never acquire a disability.

It's just a different world, and you have to accept [it]. That's their world. And it's from that lack of...I'm sure if I said to her, um, T, you know, I found that, that wasn't very cool. I'm sure he'd feel bad about it...he comes from this world, where, you know. I used to come from it too, I used to be middle-class, upper middle-class, thinking and you know oh yeah, you have to go to, you know, finish high school and go to university, and get your profession and then you know the whole bit...She can't perceive [who I really am], you know. [in her mind] I'm B sort of uneducated mental health person dealing with a mental illness...and uh you know, hard luck in life and you know ...that can only happen to someone like myself. Where it can happen to a professional just as easily. But...I think there's this concept that nothing like that could happen to someone who's educated. ON-LINE DOCUMENT: Ph 1 - Int OO*619-621 & 714.

How a person becomes transformed and learns to see him or herself as 'other' within the dynamics of a partnership group, became a central question in my mind. In my journal, I contemplated what this process might look like:

I change my view of the world as I change my view of myself in the world. And this is how others might go through a process of change. ON-LINE DOCUMENT: Journal #2 p.137.
I explored the process of personal change with one of the organizers of the second workshop in a dialogue lasting several hours. Among her insights was the following:

We can see ourselves in a political framework with very different lenses on -- either way you can connect -- this is the way I saw it before, the feelings I had and thoughts I had and this is where it's coming from -- but I'm over here now, either way you are connecting it to who you are... Every situation a chance to reconnect to who I am or who I've been...and when you are acting on something involving a predisposition about what is the right thing to do and enacting a certain position, those are the kind of locuses of generating new consciousness where you can actually say -- what are the assumptions behind this and do I still re-choose those. ON-LINE DOCUMENT: Ph 2 - Int PO*185-191.

Several ways to support change and meaningful participation were identified in the present investigation: first, making a personal commitment; second, openly examining feelings and beliefs about disability; and third, integrating an articulated commitment holistically into one's lifestyle. These points, in sequence, are illustrated in the following quotations.

I'm one of the first probably to be critical when it comes to government, but at the same time I think that some of the people we have in politics here in the province are quite committed but they... what's really needed is a whole shift in philosophy. A whole change in attitude. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*277.

I worked with women with disability in a women's centre and the best thing we did, the best benefit we had was inclusion -- that the women's centre had to reflect about what [it] means "disability," what [it] means "inclusion,"...the women's centre worker had to reflect about "What are my fears about disability?" -- to see each woman, to see them themselves in a mirror and say, I don't want to be disabled. ON-LINE DOCUMENT: Ph3D1 PAF*201.
I think that we have to be able to, to be aware that, in terms of our personal lives, because this is like what I saw in [a particular social] movement. All the rhetoric, all the ideals, all the principles that were there, but they didn't seem to transfer down into people's lives...but I do think that we have to be prepared to look in our personal lives, how things happen in our homes...And I can't say my house is a total democracy...But I guess I try anyway to keep an open mind and at least listen, before I make a decision...I do have a lot of work experiences that may not all have been about partnerships but some of them are on the fringes of partnerships and coming together for common goals and, also in my community life that's beyond my home and my job. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*220-229.

**Clarifying Level of Involvement in Partnerships**

People with disabilities have been included in community partnerships in a variety of ways, ranging from tokenism to full and meaningful participation. Some people with disabilities expect a level of equality within partnerships that they do not experience in their everyday lives:

To me, the good thing about it is people want me to be involved in partnership. They're going to include me, they're not going to disclude [exclude] me and they're going to see me as me, they're not going to see me as, as I said, a token. Include the real me. ON-LINE DOCUMENT: Ph3D1 PAF*197.

Some participants expressed concern about not having the level of participation made very clear at the beginning of the partnership relationship. For example, they may be asked to be involved in a decision-making role or a minimal consultative role; either way, some disability representatives identified a need to be told up front.
One thing is the way that a person is involved, the way they're going to let them be a partner. I mean it's risky because you don't know if you're going to be a little or a lot involved. ON-LINE DOCUMENT: Ph3D1 PAF*119-123.

People with disabilities may feel "set up" when other partners lack long-term commitment to personal change and collective power sharing within a partnership, particularly in the form of decision making. This feeling was articulated in the following quotation:

I think one of the risks that we've talked about a little bit...is that partnerships can set people up, can set the community up, and what I'm thinking of specifically, I think people who come from different parts of the community are getting tired of mainstream organizations entering into short-term partnerships that, after the money is gone, whatever the service or whatever the initiative was that you were looking at, doesn't happen because the mainstream organization doesn't have the commitment. There's no commitment at the beginning to keep the thing going and so after the partnership's over and the project's finished, access to that particular group of people no longer exists. So I think people are getting tired of being, participating in things that aren't going to have long life and they don't want to play any more. I think people feel they're being set up, with the new partnerships, they don't want to play any more. ON-LINE DOCUMENT: Ph3D1 PAF*129-131.

**Contextual Factors Affecting the Partnership**

A meaningful partnership requires its members to consider the broader context in which the partnership takes place. The context generally includes, for example, social, economic and political factors that affect and are affected by institutional systems and practices.

When the decision has been to made to participate, the context may shape the nature of this participation. One participant, for example, talked about how decisions are made on First Nations' reservations and how this
shaped the development of the partnership action plan that she would apply to her community after the third workshop (ON-LINE DOCUMENT: Ph 3 Pre ANNA*490).

The following quotation illustrates how I viewed a partner group's behavior as constrained by the institutional system which provided their livelihood. I am referring to a partnership that I observed where people with disabilities, in my opinion, were not provided with enough opportunities to have input into the project. Over time, I came to view the source of the problem as more contextual than personal.

Of course, I viewed my analysis [at that time] as correct -- upon reflection I would entertain that W and others all had different pictures of reality, different goals and that it was probably unlikely that they all would fit into that analysis and yet systematically most would because again, they chose to participate. Then there is the issue -- Who really has a free choice? I think there were -- no, I know there were individuals who were uncomfortable with the role they were playing and yet from my perspective they appeared stuck -- the system or rules of subsystems, e.g., in the case of one professional so desperate for publications that he would steal ideas/materials from the consumer group. A system of employment where another individual would manipulate consumers to think he was an advocate but use his ties with consumers to benefit himself and his institution, following direction from his boss and destroy consumer efforts -- convincing consumers to the point that they questioned themselves. ON-LINE DOCUMENT: Journal#2p.155-157.

It would appear to be reasonable then, to consider the limits of the institutions that are formally represented before entering into a partnership.

Another example of organizational constraints relates to the financial and human resources that may be available. One participant spoke of the importance for disability representatives to consider the context of the
organization they are representing in terms of available resources and priorities.

You know, if you are a small group and you're struggling just to make sure you've got enough dollars to pay your staff and then you're going to do a partnership where there are going to be shared resources and it's going to take 75% of your one and only staff person... well, maybe partnership is not the best...you know, a formal partnership is not the best thing. I think we did allude to it and it wove in and out of different kinds of conversations [during the workshop] ...You can always say no. ON-LINE DOCUMENT: Ph3 Post HELEN*253.

Contextual factors that affect individuals were identified in a discussion during the third workshop; for example, people with disabilities may desire payment for work or job-related skill development as a benefit from their participation in a partnership. The key elements of the context to consider in this situation is that many people with disabilities are poor, unemployed or underemployed.

The historical context is an important element of context for all partners to consider. Partners may not understand the reluctance of people with disabilities to participate in partnerships. The following quotation illustrates how recent history has led to this hesitation.

Everybody was doing partnerships because that was the thing to do. And I think a lot of people, especially some of the more marginalized groups got burned. Because people sort of flung themselves into this... without really understanding the long-term ramifications and the impact of entering into a relationship like this. And I think a lot of the more marginalized organizations were burned in partnerships. ON-LINE DOCUMENT: Ph3 Post HELEN*247.
Several participants emphasized that it was helpful to consider all factors before entering into a partnership; one stated, "It is important to think carefully before entering a partnership to see if it is the right thing for you, your organization, and/or your issue." ON-LINE DOCUMENT: Ph 3 Pre ANNA*488.

Summary

In this chapter I raised issues that relate to the challenges that are often experienced among the individuals and groups involved in a community partnership. Since attitudes are integrated into one's core belief system, they affect perceptions of the world, self and other. Attitudes may therefore affect opinions about the roles, contributions and communication patterns of people with disabilities within community partnerships. Tokenism is one form of behavior that is based upon attitudes. As illustrated, interpersonal dynamics also appear to be affected by a tendency to develop or reinforce attitudes in response to the behavior of others. Beliefs about emotional expression and time were found to limit the participation of people with disabilities. This chapter raised the concept of consumer control and the important role that it appears to play for people with disabilities as a means of restructuring the relations of power that exist within a community partnership. Finally, the term "meaningful participation" was introduced at the end of the chapter. This may represent an effort to reject an invitation to "participate" in a partnership as too vague. Rather, a call for more explicit arrangements for participation, in particular as it relates to power sharing, is viewed by some participants as essential. Meaningful participation in partnerships was particularly difficult when charity or medical models of disability dominated the interactions.
CHAPTER 5
REPRESENTATION ISSUES

Introduction
The materials presented in this chapter relate to aspects of representation. In the first section, my focus is on participants' experiences associated with the representation of many partner groups within a community partnership. The issues include considering people with disabilities as legitimate partners, using representative recruitment procedures and establishing equity within the partnership structure. In the second section I focus on issues arising from the experiences shared by participants about acting as a representative of people with disabilities, including prejudice and power struggles within and among disability groups. In this section I also report on how participants expressed the need for disability representatives to be vocal and supported in various ways. In the third section, "Sharing Power," I recount the ways participants stated their need to recognize their own value and power. I also record the main challenges associated with redistributing power among stakeholders and emphasize the importance of representatives being flexible in the way they see themselves and others. In the fourth and final section I deal with experiences related to a variety of issues regarding the connection between personal needs and political responsibilities in the context of acting as a representative. Various topics are explored including specifying the represented group and its mandate, employing guiding principles for a
partnership, ensuring accountability responsibilities and avoiding cooptation. The last matter discussed in this chapter is negotiating terms of participation within a community partnership.

**Representation Issues within Community Partnerships**

Three themes that affect the representation responsibilities of all members of a community partnership were identified in this investigation: people with disabilities being excluded as partners, biased recruitment methods and impacts of the operating structure within the partnership on power sharing. It would appear from the comments made, that all of these factors require consideration in the early stages of partnership formation.

**People with Disabilities Not Initially Considered Legitimate Partners**

During the interviews, several of the participants in this study stated that persons with disabilities were often not even considered legitimate partners; therefore they were not invited to participate in community partnerships designed to address issues that affect people with disabilities. The issues to be addressed by such partnerships ranged from those that directly related to disability to those that affected all people within a community. For example, one participant stated that any issue affecting a community, such as introducing a new or modified transportation system should involve people with disabilities as partners. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*346.

Another research participant explained, using the example of economic development, that the exclusion of people with disabilities may be directly linked to the stereotypical ways that people view themselves and others.
...[F]or example economic development, which we're very involved in right now -- historically people with disabilities have been left out of that whole thing because public attitude is, you know, we've got to take care of these poor little people, and most of them don't work anyway. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*228.

A related reoccurring theme was that people with disabilities should be involved in partnerships from their inception in order for their participation to be productive.

Often times the needs of people with disabilities...are an afterthought, as opposed to being in the planning process right from the beginning. So what you end up getting are these half-assed measures that really don't do anything because they weren't part of the whole planning process at the beginning. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*338.

**Influence of Recruitment Methods**

Several issues arose from the data with respect to the identification of representative spokespersons for a particular partner group, such as people with disabilities. It became apparent that these issues needed to be acknowledged and addressed by all members of the partnership. The following quotations suggest how ad hoc processes do not serve the interests of the community members who are supposed to be represented. A representative, the participants stated, should have ongoing communication with the people whose interests are being represented.

When I came in five years ago...[to the organization], somebody knew somebody in Kenora and said, Fred wanna be on the board? Well Fred may or may not have ever spoken to another consumer [person with a disability] in Kenora, which is why we have the X [a special representation network of disability organizations and agencies]. Now it's the community that gets together and decides whether it's Susan or Fred...And they'll probably
pick Susan because now it's in writing where they have to go back and share that information. ON-LINE DOCUMENT: Ph3 Post ANNA*112.

Recruitment processes may also reinforce or replicate existing, unbalanced relations of power within an institution, community or society at large. This issue was identified during the recruitment stage of the first workshop when service providers were asked to "bring" or refer a person with a disability to participate. I explored with the organizers the implications of the recruitment methods used and included the following segment in the Community Report that I prepared.

Recruiting Process: Many methods were used to recruit persons with disabilities to the workshop. One of the methods initially used was to ask service providers to identify and bring a consumer with them to a planning meeting. This process was not only limited in its success, but also the organizing group felt, upon reflection, that it may not have been the most equitable means to recruit participants. It may place service providers in an uncomfortable position with regards to confidentiality [the consumer would have to be informed before his/her name was put forward as a potential participant], but even more importantly, this process may not give consumers a similar and equal entry point to the workshop from which to be involved in the project. Other methods that were used that were more suited to the philosophy of equity that was emphasized during the workshop included contacting consumer organizations, face-to-face meetings with potential consumers and speaking on the phone with people identified through personal networks. ON-LINE DOCUMENT: Ph 1 Report*252-254.

Impact of Partnership Operating Structure on Equity

Participants frequently presented their ideal vision of partnership which typically highlighted images of equity. These images have the potential to guide the establishment of structures, such as decision-making
processes, that form the basis of a community partnership. One participant proposes the notion of voice for everyone:

In terms of partnerships themselves, I think that what needs to happen is that all people who are involved in the partnership have to have a voice. So there has to be some mechanism set up that those voices are heard and it’s...difficult because, you know when you get into multipartnerships, everybody brings their own agenda issues as well and there seems to be competition a lot of times to get that message out. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*133.

Some people with disabilities viewed their participation in partnerships, by itself, as a means of establishing greater equity, in a manner that allowed people with disabilities to gain more influence merely through their associations with others who had power in society.

Yeah, because if you're out there sort of rubbing elbows in the business community and with government and politicians on an equal footing, rather than always having to go to them to their office or whatever, then you have a greater influence on them. ON-LINE DOCUMENT: Ph3D1 PAF*193.

On the other hand, a number of participants told how they have been excluded or had influence reduced within a partnership structure. This repercussion might occur when partners are regrouped to form special committees. For example, as mentioned, one week after the first workshop, it was proposed that a core group comprised primarily of service providers be formed to guide the activities of the project. One of the participants present indicated the problem of developing special grouping which would leave some people with limited access to information and fewer opportunities to give input.
Should they think that, instead of dividing into groups -- [that] we all, always in anything, any endeavor, that we should talk about just in one group -- so everybody hears the first-hand information. I can't believe it -- how did he arrive to get a core group? ON-LINE DOCUMENT: Ph 1 - Int MO* 307-311.

Another participant recounted how her partner group, people with disabilities, were systematically removed from a partnership after years of planning, just before the implementation stage of the project. This action was taken by the partner that controlled the funding of the project.

NO We feel they've cut us off and now they're implementing it. We know they don't have accurate information, and the understanding, and...

KK And yet, they're the funders. They've got the money so they've got the control?

NO Yeah. Which is unfortunate, you know. After working with them for so long like that. Now, believe me, it wasn't smooth sailing either. But all of a sudden, you know, we're forced into a position where we have to write pretty strong letters to, you know, get any response or any kind of reaction. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*124-127.

Another way that several participants representing people with disabilities in partnerships experienced a loss of power was when the voting structure around them was expanded; although they were allowed a vote, the increase in the total number of voters diminished the impact of that vote.

One participant described her efforts to have more participation of people with disabilities on a partnership committee by asking disability-related service organizations to send a representative who had a disability. In this case the able-bodied representatives refused to give up their seats but agreed that they would each invite a person with a disability from their
organization. As articulated by this participant, this arrangement had the effect of involving people with disabilities in a manner that did not allow them an opportunity to speak freely.

Plus they (people with disabilities from the service organizations) don't want to go against their own organization, you know. If their organization wants an able-bodied person representing them and the partnership committee says, no, we want a person with a disability representing you, then that kind of puts the person with a disability in an awkward situation with their own organization...None of the organizations were willing to give up their seat. So what they came up with was each organization was to send one staff and one person with a disability...So it doubled the size of the committee, mind you. But it tended to work out a little bit better. Even though I guess it didn't give the people free enough room to speak. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*194-200.

This illustrates that the mere presence of people with disabilities does not mean that the interests of people with disabilities will actually be represented.

Some of the ways that consumer power was diminished within a partnership were described as subtle. For example, one participant spoke of how chairing a committee, while giving the appearance of greater control, also resulted in limiting her participation.

We are chairing the meetings. Often times, you know, I might be asking questions like, okay, where do we go from here? What does the committee wish to do? So, in chairing the meeting, I'm actually eliminating myself from the participation process a lot of the times. Now, that doesn't mean I can't participate, it just limits my participation in some ways. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*495.
One of the basic prerequisites that the participants discussed for facilitating equity within partnerships was the provision of access accommodations. Accommodations might include, for example, providing alternative forms of communication, such as sign language interpretation or blind-deaf intervenor services during meetings as well as alternative formats for printed material (disk, audio tape, braille and large print). In addition, there are physical accommodations that range from providing ramps to omitting perfume scents if a participant has environmental sensitivities.

One participant discussed ramps for getting into a building where meetings were being held; she stated, "there are barriers to their participation...In terms of even being able to get to the place where people are meeting to discuss things." ON-LINE DOCUMENT: Ph 3 Pre DIANNE*332-334. Another participant depicted his idea of "holistic access to equal results" as a concept that went well beyond a traditional notion of "equal opportunity." In his view, having a ramp into a building would not be enough; one would also need to consider things such as providing people with the full range of incentives for wanting to access the building, such as employment and providing technologies or interpreting services to facilitate full access to information.

Instead of using the term of 'equal opportunity,' I would use 'equality of results'...So I provide the opportunity to go to the building to anybody, including the people in wheelchairs, why that person in wheelchair is going into the building depends on the result...And the other thing is I would use the term of holistic access, because I think that covers everything from...using different technology, to use of different language. ON-LINE DOCUMENT: Ph3D2 ROLE PLAY*91-95.
Specific Representation Issues within the Disability Community

Several issues arose in this study that have implications for people with disabilities in their efforts to meet their representation responsibilities. This includes the recognition that discrimination in various forms exists and is reinforced by people with disabilities themselves. Power struggles among disability groups were also identified as a distraction from meeting community needs. Finally this section covers issues related to locating and supporting vocal disability representatives. These factors have implications for people with disabilities who want to work to ensure that their participation in partnerships will meet the needs of community members who have disabilities.

Disability, Gender and Cultural Discrimination

Notions that prejudice and conservatism exist within self-help movements ran counter to expectations, including my own and those of several participants in this study. One participant stated, "When I first started working in the self-help aspect of things I had an expectation that the disability community, for example, was not going to have elements of conservatism in it because of the ideals that, for me, the whole self-help movement stands for." ON-LINE DOCUMENT: Ph 3 Pre HELEN*221. When I asked for confirmation and elaboration in a second interview she described the impact that this realization had upon her emotionally.

KK Right. So when you go in and do work within the self-help movement you have greater expectations around acceptance and sometimes that can be even more difficult when you have people from those groups that are supposedly working on acceptance issues themselves, dishing out the same kind of "isms"?

UO Exactly. And, as I say, I intellectually understand... I mean I have an intellectual understanding of why that is, but my heart is always taken by surprise...I mean, it's
not a condemnation at all. I certainly recognize where it all comes from. ON-LINE DOCUMENT: Ph3 Post HELEN*217-219.

This participant had come to realize that people with disabilities, like all other people, are influenced by social forces such as prejudice and a desire for control even if it involves oppressing others. Within this study, participants identified several forms of discrimination.

One participant gave details of how people with certain types of disabilities were discriminated against by other members of an organization that supposedly had a cross-disability mandate.

I just was really freaked out by a couple of those, those attitudes -- people coming to our AGM and saying "Well you shouldn't have allowed certain people to speak or make those noises," because we had someone who is nonverbal and has cerebral palsy... We were talking about our topic, and she was excited, because that's like her favorite thing, and so she comes all the time, and she was excited and she wanted to let people know that, you know, it was a good thing...and so she yelled, you know, because she couldn't speak, couldn't put up her hand to say, hey ya I really like this, so she just kind of made a lasting kind of yelling noise, we didn't care, we were happy. Other people said to us you shouldn't have even let "them" be there...someone who'd had a, like a psychiatric disability who got up and started to speak about whatever it was he was concerned about, and to us as staff we understood where he was coming from because we know him very well, but other people who were members of the centre thought, no, he had no right to get up there and say anything, hm, it's like excuse me, I mean these were highly university-educated consumers, who were saying these things...and I'm thinking, ya, you're no better than anybody else, thank you very much. ON-LINE DOCUMENT: Ph 2 - Int QO*379-395.

These types of behaviors reinforce what is known as the disability hierarchy among people with disabilities.
The types of discrimination that were recounted by participants were not limited to ablism. People also spoke of a lack of gender representation within disability organizations and the lack of inclusion of people of different ethnicities.

A challenge that was largely expressed by the women working within the Independent Living Resource Centres was that a feminist approach was not popular within the centres. In fact, participants indicated that while the staff tended to be female, those in higher positions of power tended to be men. One participant said, "There's formal power brokers and informal power brokers, and they're mostly all men, they're all men." ON-LINE DOCUMENT: Ph 2 Report*134-136.

Responding to people who live in different cultures and different ethnic backgrounds, the aboriginal community is something we're still exploring, so I think, you know, the little white guys, basically have done fine by the movement but... ON-LINE DOCUMENT: Ph 2 Report*195.

This phenomenon was not merely associated with the disability community in this study, but also other social-action groups such as the women's movement. A participant who had a long history of working within the women's movement described what she considered to be an unhealthy approach that mainstream women had toward other women in the movement.

A number of years ago, when, ah, before immigrant women had a stronger voice...disabled women, low income women -- it was sort of white middle class women that were sort of speaking for everybody...trying to improve...the situation of these other groups. These other groups are becoming more empowered all the time, and are speaking out for themselves and sometimes what they're saying is not in agreement with what the original white middle-class
crew are saying...What I'm starting to find, which I find really disheartening, is a lot of intolerance from this original white middle-class [group]...it's almost like they want to keep them victims...within the women's movement...you can't get anything more unhealthy than that. ON-LINE DOCUMENT: Ph 2 - Int TO*255-275.

Power Struggles within the Disability Community

The responses of the participants suggest that power issues need to be recognized before they can be addressed within the context of partnership. According to consumer accounts, conflicts at the community level appear to diminish the energy that might otherwise go into supporting the partnership, its working relationship or tangible outcomes. As one participant said, "My idea of partnership is where there's mutual loyalty and respect and that is what I would consider ideal partnership. But I just see tremendous war. It's not only in the disability community, every community." ON-LINE DOCUMENT: Ph 3 Pre GERALD*127.

Turf wars may be linked to different philosophical approaches. One participant spoke, below, about how she believed that the way to approach this situation was to agree to behave according to a certain set of principles within the partnership:

I find that [turfing] is a huge problem inside the disabled community and I think that we could be of benefit to each other by just...making a statement, a really strong personal statement that the object is to work together to[ward] a common goal and you can go back outside of that partnership meeting and do your individual activities but for the benefit of a strong working partnership... ON-LINE DOCUMENT: Ph3 Pre ANNA*244.

One of the difficulties raised was that of shared ownership of the partnership. One participant gave details about a situation where a partner group, on their own, improperly issued a letter to the public.
If there's three or four consumer groups working together in a partnership and all of a sudden somebody sends a letter out...on their own letterhead, it's not going to work because that person is taking ownership of the partnership, and it's not a collective partnership...if there's going to be any vision that you're not a unified group coming to the partnership, you're going to lose your opportunity to create it. ON-LINE DOCUMENT: Ph3 Pre ANNA*244-248.

Addressing the problems among disability organizations was seen by some as a priority that must be addressed before efforts are made to form partnerships with other sectors.

We have to fix those inherent problems or we're never going to be forming wonderful partnerships because we can't get our own act together. I think the first partnership we need to own is within the disabled community ourselves. I think the first partnership when we all talk about partnerships, the first partnership we have to learn how to form is within our own disabled community, and increase the communications, and increase people's potential for leadership development and all the things, and pull people who don't have those skills in and mentor them along. ON-LINE DOCUMENT: Ph3 Pre ANNA*348-360.

In addition to the conflicts between organizations, participants involved in the third workshop discussed the need to break down hierarchies between individuals who have different types of disabilities.

We need to build partnerships within our own organizations to eliminate the power and control hierarchy within the consumers themselves, so that this consumer thinks that they're better than this consumer, because that hierarchy is there and I think we have to acknowledge it's there and I think we have to deal with the fact that it's there, fix it and then go on collectively to form the partnership. ON-LINE DOCUMENT: Ph3D1 MURAL*25.
In my journal, I reflected upon a meeting associated with a separate research project in which many disabled participants shared their experience of oppression within the disability community. They had also recognized the fact that oppressive relations may be replicated by people with disabilities who themselves had experienced oppression at the hands of others.

In the room many of us shared the experience of or the revelation of oppression within the disability movement. Many of the participants, e.g., A, T and I had thought at a deep level about what we are doing in the larger context -- with respect to power in society. ON-LINE DOCUMENT: Journal #3 p.213.

In an interview with one of the organizers of the second workshop, I explored the ways one might challenge disability organizations to address these issues. We discussed a scenario where members of a disability organization were not providing access accommodations to people with disabilities, which countered their organizational mandate to promote inclusion of all people regardless of disability within society.

KK  If you have a group and their principle is for example, equal access for people with a variety of disabilities, and you have a disability group that is not providing equal access to its members who come to meetings...What do you do?

PO  First, expect it, second of all, you have to say, do you try to deal with it that involves telling someone "you're out of line here" and evoke -- get a sergeant or a colonel. In terms of women's organizing, we used to talk about lesbian police. Those things of enforcing internal codes of behavior -- to get people in line and going to someone who is a recognized authority -- a sergeant in the army -- that is all a certain kind of behavior that may or may not work...

[telephone call interrupted interview]
What I was talking about [was]...how some of the assumptions I have made -- erroneous ones -- include people who have experienced oppression would value democratic communication process.

What you actually said was [you] believe in democracy and what that does is perpetuate the assumption that people are acting out of a belief system in the world as opposed to reacting to their experience of life...saying this is a group of people who would like to see it created and who are going to get together to create democracy and that is a very different process...is very different from saying we have all figured out what is wrong and we have the answer and now we are going to figure out how to convince other people that we have the right answer.  ON-LINE DOCUMENT: Ph 2 - Int PO*209.

In this quote, this participant emphasizes the need to be open-minded in the approach to finding answers to problems.

The Need for Representatives who Speak Out

The need for strong, vocal disability representatives was clearly identified by several of the participants. One of the situations narrated was as follows: "When mental health consumers sit on a committee with the medical, people from the medical profession...we could have ten mental health consumers sitting at a table with six people from the medical profession and they're still going to overpower us, you know?"  ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*208-210.

The problem arises, however, that strong and vocal disability representatives can be hard to find. One participant considered the problem to be "culturally conditioned dependence":

People who have been culturally conditioned into dependence and think that, you know, as long as they're docile and pleasant that everything will be fine...There is a cultural dependency with disability, I find, that people, because they haven't been given decision
making, they haven't been given their own power in their own lives, that they become reliant on others to make decisions for them, to provide for them, and to tell us when and where to do what and how...if you have been dependent on the social service system to provide your well-being, provide your food, clothing, and shelter, then you are going to be, in this culture anyway, you're not going to rock the boat. ON-LINE DOCUMENT: Ph 3 Pre INGRID*437-449.

Several of the participants had used approaches to attempt to deal with the problem of overwhelmed representatives, including increasing the number of consumer representatives and identifying representatives with high self-esteem.

Sometimes you might feel like you're overpowered because some personalities are very strong. So when we set up any committee...we're very careful that we have enough consumers on it that are relatively vocal, strong, opinionated, and stuff like that, that aren't afraid to voice their opinions. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*120.

You need people with self-esteem that are willing to speak up, you know? You can have honest people with disabilities sitting on the committee, but if they're not willing to voice their opinion they tend to throw the committee out of whack even further, because it looks like it's consumer controlled, but it's not. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*130.

**Support for Representatives**

Participants indicated that in order for people to be effective in their role as a disability representative in a community partnership, they often required support. Participants talked about a variety of ways that disability representatives could be supported. These supports include government funding of community-based organizations as well as specific services provided by staff persons of these organizations and the commitment of all partners to make a partnership accessible.
Several participants both from disability organizations and women's organizations spoke of the need for various forms of economic support for their organizations from government. Their descriptions made it clear that a lack of funding reduced the availability of staff persons to address community issues through a partnership approach.

One of our women's centres closed the doors because they were operating with such limited funding that it actually started, it just started getting at everybody. I mean it was wearing on everybody's nerves, they were relying on volunteers and that wasn't working...they were so damn underfunded...it was stretching everybody...to the point where then it affects your family life, I mean it affects every friggin' aspect of your life. ON-LINE DOCUMENT: Ph 2 - Int TO*933-947.

Disability organizations were seen as necessary for supporting the voice of disability representatives. One participant presented a novel model for ensuring consumer control of a multisector partnership that required all major decisions of the partnership committee to be approved by the board of directors of her disability organization. She outlined how this structure and process allows consumer representatives a second chance to explore issues; for the model to work, a disability organization has to be available to play a central role:

The idea is that people with disabilities control the process...or at least the outcomes. Like if you have someone on the committee that has an opinion, a person with a disability, and they're afraid to speak up at that time, when we go back to our board meeting to approve what the [partnership committee] has decided they may feel freer to bring it up at that board...And then it would be evaluated by the board of directors...So they do have that little bit of leeway. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*461-463.
There were several ways that all members of a partnership were seen as responsible for supporting the meaningful participation of people with disabilities in partnerships. The following quotations illustrate prompting with plain language, a buddy system and training in access accommodation services.

*Prompting with Plain Language*

One participant involved in the third workshop required whisper translation: the simultaneous translation, upon request, of complex concepts or terms into plainer language. At times, she also required prompting which involved supporting her in communicating her ideas in a clear and organized fashion by reminding her of her ideas at key moments in time. Many workshop participants, myself included, had an opportunity to learn directly from this woman when she invited us to whisper translate during group discussions and prompt during her presentations. She spoke in an interview about the need to not only support but to prepare disability representatives such as herself.

I think they may have, if they're going to want a person with a disability, prep them. Prepare them, like some people need this, because I've been in it so long. I wouldn't, but I'm talking about if someone came in new and they weren't as familiar [with] how things go. There should be a prompt thing, this is what we do in partners and this is how the thing is going.

*ON-LINE DOCUMENT: Ph 3 Pre EMA*227-231.

*Buddy System*

The participant who made the above statement, elaborated on her use of a buddy system when she worked as a representative in a partnership.
Although this type of approach has many advantages for anyone in a representative role, this participant detailed how the buddy system assisted her with understanding and accessing information, strategizing and advocating for the access accommodations that she required from the other partners within the partnership. She explained that these were the supports that she needed in order to be a productive participant.

KK  A buddy? How does that work?
E  Well, what happens is we, as we say, when they throw it all back, I take it back and say, hey, look, you [disability organization] asked me to represent us on this committee and they [the other partners] are throwing me all this information and they're not explaining it well, is it worthwhile for us to stay? And then we'll review it and then also we'll get one of the persons from one of our organizations that we're working with and say [to the partners], you're throwing all this information at us. We need more understanding of it and we need it not thrown at us and, of course, they say, well, we'll try better next time.

KK  So is the buddy somebody from [your organization]?
E  Actually my buddy is our president...she understands my disability and I think that it is interesting for her to be involved because she knows the needs and when I need clarification and when I don't. ON-LINE DOCUMENT: Ph 3 Pre EMA*235-259.

Training

The need for partnership training was identified during group discussions among participants of the third workshop. Within this discussion, participants spoke about the value of training people with disabilities to play an advocate role.

Many times we assume the position of an advocate but really aren't quite sure how to go about it and so you just go to these meetings and you just stumble through, but there's no formal training that says, this is how you deal with these things, things that give you
confidence, that you know how to deal with these different things. ON-LINE DOCUMENT: Ph3D2 ROLE PLAY*138.

**Sharing Power**

Participants in this study raised several issues related to sharing power amongst the members of a community partnership. These factors appear to be linked to the way people view themselves and others. The findings imply that flexibility in the way we view, create and act within these roles is important.

**Recognizing One's Own Power**

Several participants spoke about shifting the way they viewed the invitation of becoming involved in a partnership. Some disability representatives said that they felt grateful for being considered, in a manner similar to that expected of someone playing the "disabled role" as described in the previous chapter. As one woman phrased it, "I suppose we should consider that a step forward, right? That people are at least trying to include, you know, by inviting you to partnerships and inviting you to participate and those kinds of things." ON-LINE DOCUMENT: Ph 3 Pre INGRID*239-241. This appears to be particularly relevant to people with disabilities who commonly experience rejection. This grateful reaction, is illustrated in the following dialogue that took place with a woman before her participation in the third workshop:

**KK** This question is about partnerships. Can you describe what partnership means to you? What do you think of when you think of community partnership or someone is coming to you and asking you do you want to be part of a partnership or does [your organization] want to be part of a partnership? What are the things that come to your mind?
E Well, the first thing is, wow, they want us to work together, you know. Gee, they want us to be involved, even though we, some of the things we do are different than them, but maybe they don't want to see us as different. They're working on the same thing we're working on.

KK So it's excitement. They're interested.

E Gee, [own name] is getting involved in this and they want her to get involved... And also too for the organization. ON-LINE DOCUMENT: Ph 3 Pre EMA*90-96.

The participants of the third workshop discussed the assumed equity within partnerships in some detail. They spoke of how being grateful resulted in giving some of their power away and how in some cases partnerships may be used as a smokescreen for motives other than altruism. As illustrated below, they discussed the importance of recognizing their own value and power.

Often we come from a situation where we're so thankful that people want to be in partnership with us, so we even undermine ourselves when we go into the partnership. You know, it's so good of you to come and sit down at the table with us, but by doing that we place the other person up on a pedestal. ON-LINE DOCUMENT: Ph3D1 PAF*157-159.

We just get so grateful and we just get so hepped up. Oh my god, they're paying attention to us and it's nothing, it's a smokescreen. ON-LINE DOCUMENT: Ph3D1 PAF*277.

Just as some behaviors tend to diminish power, other behaviors appear to create power. One woman described how she worked to recognize opportunities when her organization could use political tactics in order to gain power.

All of a sudden, you know, we're forced into a position where we have to write some pretty strong letters...When things go [poorly]... we'll do nice first. When nice stops working we get
a little stronger, write some pretty strong letters, go to the media if we have to. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*127-129.

**Redistributing Power**

Some participants presented detailed descriptions of the difficulties that they perceived others had in giving up power traditionally held. Some people had to learn how to play a new role altogether. Others faced barriers related to the institutional structures on which their employment was based. As illustrated in the quotation below, this disability representative had a clear understanding of the many demands that may be placed on other partners.

I ...it was a real frustrating experience for those who traditionally held power. But in the end, you know...like with any community development thing, it takes a lot longer than you think it's going to...but in the end I think there was lots learned on all sides...

KK And those people that have power end up feeling frustrated, maybe because they have to give up a little piece of that power?

I Well, because they have to give it up and they don't know how. And so you have to help them learn how to do that and still respect their masters...dealing with funders and various levels of government, everybody has a whole slew of masters that they have to please, so they may get into the spirit of the partnership, right, in a true spirit of partnership, but still have to make it fit those little boxes and squares that they have on all their forms....So I think that was the big frustration...once they bought into the concept and to try and fit it back into their day-to-day work life and all the accountability things that they had to do. ON-LINE DOCUMENT: Ph 3 Pre INGRID*89-104.

The institutional structures and political contexts of various partners appear to make forming a new partnership very difficult. As one participant
explained below, electoral systems and professional associations tend to be built to help certain people maintain their power:

Like if you're trying to establish partnerships with people who already have some control or some power in that area, it's really hard to get this kind of partnership where there's some kind of equality going -- if, for example, you're working with people who are in elected positions or if you're working with people who are in professional associations such as lawyers and doctors, they already have a piece of power that in some ways they either have to relinquish or share, but it's difficult because the way the systems are built, they're built for people to maintain those powers. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*129.

Questions raised about the feasibility of truly sharing power are posed in the following excerpt:

So sometimes I question in fact whether we really are able to create that partnership because people don't walk into them equally. We just had a change of government here...and the election platform of the government was building partnerships, right? But I wonder how do we do that when we have people who are elected and they're controlling the public agenda and they ultimately get the final yea or nay if something is going to change or if there is something new to be introduced or something to be gotten rid of. ON-LINE DOCUMENT: Ph 3 Pre DIANNE*131.

As the following quotation from an organizer involved with the second workshop illustrates, it may be difficult to create equity when a partner's experience with it is limited or when a partner has not committed to the process of working on achieving equity:

You say you want equality but you have no clue what the process of building equality is...words become meaningless because the practice is so divorced. We do ourselves a real disservice when we let our language be colonized because we don't insist on the integrity of
the process. There is this idea that we are always -- in terms of anything that is real -- anything that is anchored in the truth of someone's experience -- is the truth of a living being. We are always moving from whatever that truth is internally to the outside -- to the interaction. My ability to be honest with myself becomes the ability to be honest with you -- our ability to be honest with each other because of an authentic process. When we are not honest with ourselves about willingness to become a participant in the creation of respectful "equality"...in terms of the individual being committed to the eradication of dominance and subordinate power relations. If that is what you are trying to live -- you are part of a movement that says that is its goal and then the values are supposed to be the articulation of how you will reach that goal and we've seen in the past 15 years a move away from goals onto values and onto process a bit -- but now I think the challenge of the 90s will be how can the personal process of involvement [be] in this movement. ON-LINE DOCUMENT: Ph 2 - Int PO*81-86 & 247-249.

**Flexibility in the Ways People See Themselves and Others**

The ability of the partners to share power appears to be linked to their flexibility in how they portray and define themselves as well as the way they are able to view others. One participant talked about how she wanted to portray herself among other partners in a manner that was more holistic than her traditional role of service provider in the community. She hoped that participants who had a disability would be more expressive and less threatened than they would otherwise be in their community interactions with professionals.

Through my sense of humor, hopefully my sincerity and just generally being with people for a week so they get to know you, they saw me as a person rather than a professional in a professional role and they saw me more as a human being through role-play, through interaction with them, through serious moments, through jovial moments...I think it was a good opportunity for people to see a professional in a human role rather than as a professional. ON-LINE DOCUMENT: Ph 1 - Int KO*171 &185.
I think they need to feel that they are free to express themselves without being threatened with a professional there and to realize that the professional is there not as a professional but that the professional is there as a friend who isn't going to document it, write it down, and report on them. ON-LINE DOCUMENT: Ph 1 - Int KO*209.

Although the desire for a shift in the way people see themselves and one another was made clear by some participants and organizers, it became apparent at a community meeting, one week after the 4.5-day partnership workshop, that the issues were complicated. At this meeting, as earlier recounted, dominant members of the group had proposed to establish a core group of primarily professional service providers to continue with and control the project. This episode highlighted the need to look at the deeper structural and interpersonal factors that work to make such shifts in individual and collective identities difficult to make and maintain.

Regardless of the opportunities to encourage sharing of power during the first partnership workshop, it was apparent from the interview dialogue that several participants clearly continued to view participants in terms of their location in a hierarchy of power. One participant who has a mental health disability said,

She's taken the steps to try to understand, and to try to go past and to treat people like real people. And I think people treated everyone very respectfully there. But I even felt at the end of the week that the lines had been drawn [between us]. ON-LINE DOCUMENT: Ph 1 - Int OO*583.

Another participant, who represented the interests of senior citizens also described the hierarchy that he saw among the participants. He said that technical people such as psychologists were at the top of the hierarchy.
They were just above the program administrators including the executive director of the disability organization that coordinated the project and the service provider administrator who participated. These people were seen to have more power than the care-workers who worked directly with people. At the bottom of the hierarchy were the people who received the services, such as people with disabilities and senior citizens. ON-LINE DOCUMENT: Ph 1 - Int LO*953-1006.

**Personal-Political Issues**

One of the central themes that arose from the data of this study was that political issues and actions are interwoven with an array of personal issues. This section describes methods raised by participants that have been used to try to address these issues so that they create less havoc within community partnerships.

**Understanding the Group Represented**

There are many ways that personal issues may affect the political act of representing a group within a community partnership. Participants mentioned methods for dealing with these problems, including making one's personal positions and political responsibilities clear at the outset. Several participants suggested that representatives should identify and clearly ally with the interests of the members of their partner group. One participant also pointed out that it may be challenging to resist being "swallowed" by other, more powerful partners.

My mandate is not to work for the city [the partner], my mandate is to work with the city for the consumers in this community. You can be part of the system but you must maintain
your perspective. Don't get swallowed up by the system. That's the warning. You must go into that partnership maintaining your perspective so that you don't lose sight of why you're there and get swallowed up by the system...with some pretty high-powered players sometimes in partnerships. And if they don't respect your perspective and maintaining that perspective, then I think it's time to reassess the partnership. ON-LINE DOCUMENT ANNA*246-248.

Several participants depicted how they found it difficult, on occasion, to recognize those times when they were acting on behalf of a particular group of people rather than their own personal experience. One participant discussed how he ran into trouble when he tried to negotiate the relationship between partners by wearing two hats at the same time.

I mean, I really got into major trouble. You know [I was told], "you're into a conflict of interest here. You can't...you have to decide what side you're on" -- all this kind of stuff, you know? So I'm recognizing it's not very easy to negotiate a partnership. ON-LINE DOCUMENT: Ph3 Post GERALD*355.

Another woman spoke of how living in a small community made it particularly hard for her to keep track of whom she was representing at times.

And here in [a small community], it is so small...so the relationships that people have, and I know this may not be a great choice of words, but what really describes it is there are these kind of incestuous kind of relationships that happen, because people are involved, you go to sit in one meeting and it's, well, am I wearing this hat or that hat? And who am I representing at this meeting or who am I representing at this particular event? And I've gotten caught, between being an employee [of one organization] and being a board member [of another organization]. And been asked, "Well, who are you representing here?" ON-LINE DOCUMENT: Ph 3 Pre DIANNE*291-293.
The data also indicate that recognizing different voices within the represented group was crucial. In a group, participants may be at different stages of learning or personal development. When describing an information conference that her organization hosted, one participant recounted,

This is another thing I really have a problem with...we're all from different places, and we're all in different places of our lives, with different skills, different whatever. We had a conference a few years back on sexuality, and one of the issues that came up is that some of the consumers were very upset at the fact that we had done it [provided information at the workshop] on a range of issues, so that for someone who had no experience whatsoever and had basic questions could still get that information, or, you know, people who had more experience and just wanted to share with each other could have had that opportunity if they wanted to use it. ON-LINE DOCUMENT: Ph 2 - Int QO*341.

The crucial importance of responding to diversity within the represented group was exemplified by one participant who considered it to be a prerequisite for a strong social movement.

I think a strong movement also has to be [responsive]...to the diversity of the population of disabled people, and I'm not sure we're there yet...I think there's a two, two aspects here. One is making sure where we're responding from is truly reflective of all the disabled population and the needs that might be there. ON-LINE DOCUMENT: Ph 2 - Int UO*181 & 583.

It was pointed out by several participants that people with some forms of disability are seen by members of disability organizations and members of the general public as more legitimate or effective representatives than people
with other forms of disability. The following example highlights the importance of becoming aware of and resisting these influences:

A couple of weeks ago a group was doing a protest, right?...They called and they wanted somebody there for this protest and this woman, who's supposed to be enlightened...says it would be really great if somebody with crutches or in a chair would be able to come. We said, well you're not getting anybody, ever!  

**Clarifying the Mandate and Philosophy of the Represented Group**

Holding onto guiding principles associated with a group or organization within a multisector partnership was reported to be challenging. Some participants expressed concern about not wanting to feel compromised. Adding to the complexity of this task, others identified a need to view issues from the perspectives of many stakeholders, simultaneously.

How do we therefore uphold our own principles, and not feel we've compromised those as we partner with other groups.  

We have developed our own way of thinking, our own way of looking at the world, as has any movement. And what we have been looking at is how our needs are not met in this world and we've gotten very good at saying how they're not met...and that's fine, but the fact of the matter is we're all in this world together.  

Participants often stated that it was crucial for representatives to clearly present the mandate or philosophy of their partner group or organization. In the quotation below, a participant described how the Independent Living philosophy formed the backbone of action taken, yet
there were different interpretations of how this guiding philosophy might be put into practice:

The philosophy...you know representatives from all the different centres, and I really find it to be a backbone, like people are constantly going back to reflect on it around making decisions about what to do in the organization, what to do about one particular individual who is struggling with something, so I find that is really really used. Now, of course it’s open to interpretation and different centres have chosen to interpret it in different ways. ON-LINE DOCUMENT: Ph 2 - Int RO*125.

Opportunities arose during the second workshop for participants from disability and women’s centres to explore issues related to using strong organizational philosophies. One participant expressed her reluctance to accept approaches that were considered generalizable across all women’s centres; she emphasized that centres have different value assessments and priorities:

I’m not always in accord with the other women’s centre people on this one and I feel too that what may be a good policy to advocate for some women may actually adversely harm others. ON-LINE DOCUMENT: Ph2 Report*110.

On the basis that what is good for one person in an Independent Living Centre might not be good for another one, therefore, they can’t lump everybody together, I would say. ON-LINE DOCUMENT: Ph 2 - Int SO*382.

Another participant who works at an Independent Living Centre, detailed the work involved in continuously interpreting the Independent Living Philosophy in a specific situation in order to guide everyday practice. She recommended open dialogue:
I know that within our staff here we've several times, like I've had, I guess myself, and my boss...we can see it, from the same kind of way, so that we don't usually argue on the way to proceed, but every now and then, you know, we have real difficulty with, um, deciding how...things should go. We have to remind each other what do you think that is really in Independent Living philosophy. ON-LINE DOCUMENT: Ph 2 - Int QO*375-411.

Participants emphasized the importance of recognizing that all people within a particular social movement will not share the same values. Variables such as culture and geographic region, they suggested, may impact upon the way issues are addressed. One participant who was involved with women's issues in a community in the Northwest Territories spoke about how her centre differed from many others on the issue of gun control.

I think that sometimes it's..."Dear woman, you ran a women's shelter, you should agree with us." I ran into this over the gun control issue at a conference I was at. Because I come from a [Northern Canadian] society where gun control doesn't make any sense at all. ON-LINE DOCUMENT: Ph 2 - Int SO*296.

Leaders from both the women's centres and the Independent Living Centres who were involved in the second workshop cautioned against dogmatic approaches that pressure all people within a certain social movement to act in prescribed ways.

The behavioral ethic [is] "trying to get everyone in line -- a thinking line if not a physical line. If we think that that is our goal and that our power comes from when we can all act as a unified voice then what we are doing is imposing the same dead nonthinking, noncreative interaction between ourselves...this [is what] dominant culture is made of. ON-LINE DOCUMENT: Ph 2 - Int PO*29.
As the following quotation illustrates, the participants made it clear that putting philosophies into practice requires a continuing effort and flexibility:

It's all really important but I also think there needs to be a little bit more openness in terms of adapting the way we live out those principles and the way we problem solve around the implementation and living out those principles, given that we have changes in our environments -- social, political, economic. ON-LINE DOCUMENT: Ph 2 - Int RO*147.

**Influence of Personal Needs on Representative Responsibilities**

Through this study which provided me with an opportunity to talk to many disability leaders and reflect upon my own experience, I learned that it may be impossible to separate the individual who participates in a community partnership from the political, social and economic forces that affect his or her life. The importance of partners recognizing an interaction between these two variables became apparent.

Several participants stated that they found that some disability representatives appeared to be serving their own personal interests.

But there are all kinds of people, there are people who like the glamor, they like to hobnob with politicians, and there are others who like action. That is in all levels of society but don't forget that the issue of individualism is highlighted here in this society so most of them...have a tendency to work...by themselves, and their disability. ON-LINE DOCUMENT: Ph 3 Pre FABRICIO*295.

A number of participants stressed the importance of recognizing what each individual brings to a partnership, in terms of personal history and understanding of the issue to be addressed. One participant stated:
How does it go... it says, "Wherever I go, there I am." And, you know, for me it's sort of that notion that you bring all of you. You don't leave -- although there's an expectation that you're supposed to -- you don't leave everything that built you, contributed to who you are today, you don't leave that... It comes with the package. So, you know, it's all wrapped up in sort of a... it's not always conscious, but when you kind of bring the light to it, you can see how it fits in. So I think my definitions and idea of partnership has been influenced by all... of my lived experience. ON-LINE DOCUMENT: Ph 3 Pre HELEN*199-203.

The following excerpt illustrates how I explored issues of personal benefit in my journal and expressed a number of my beliefs about the responsibilities of disability representatives within community partnerships:

Reflections on experience [with disability group involved in partnership with other sectors]:
I saw people with disabilities who were not as attached to the principles of collective empowerment as they were to personal ladder climbing or improving the situation for people with their specific disability. I also saw what I think might have been fear-driven fence-sitting way beyond my point of tolerance. ON-LINE DOCUMENT: Journal#3 p.79.

I considered the possible effects of having a representative who, through personal experience of living with a disability, has learned to expect very little from others. I wondered whether this experience might account for the "something is better than nothing" approach that I witnessed among a few disability representatives. ON-LINE DOCUMENT: Journal#4 p.10, 11 & 12.

I analyzed the interaction between the personal and political activities in my thesis journal. I contemplated whether a person might be able to easily represent others when their basic personal needs have not been met. The personal benefits of participating in a community partnership for an individual with a disability may include an increase in self-esteem. In my
personal journal reflections I linked participation in activities of a disability organization to politics, identity and a sense of belonging. ON-LINE DOCUMENT: Journal#4 p.147.

Although these issues exist for all of the people involved in community partnerships, I began to consider during the study that there may be certain forces that are prevalent for people with disabilities or members of other groups who have experienced a great deal of oppression and exclusion. People who live with a disability are often struggling for acceptance from others within the dominant culture and may therefore experience personal pressure to adopt values that are prevalent within this culture rather than challenge them. Based on my direct experience within the community and my involvement in conducting interviews with disability activists for another project, I came to believe that those who go against the grain of dominant society often experience greater personal stress and isolation from both the disability community and broader society. Others who work within the dominant framework may receive accolades and acceptance from people in positions of power.

**Cooptation and Manipulation**

The issue of cooptation was raised by several participants. I can best describe the participants' understanding of cooptation as a process that takes place willingly or unwillingly when representatives become overwhelmed by the agendas of others rather than resisting these forces and maintaining a clear idea of their responsibilities and the goals and values of the group they represent. As illustrated below, one participant identified the risk of cooptation when agreeing to represent people with disabilities in a partnership:
I see...that's one risk...in a partnership...is to lose the sense of why you are there, you lose focus, who you are representing and what you are trying to achieve, in that negotiation that goes back and forth...which is really easy to do... when you have people with disabilities that they are struggling through life and suddenly, you took them on a tour around the country, every single day five-star hotels and you see all that part in which people become coopted. ON-LINE DOCUMENT: Ph3D1 PAF*139.

Since agreeing to participate may be interpreted as supporting the values of other partners or all aspects of the partnership project, some participants in this study emphasized the need for disability representatives to recognize how their participation in partnerships might be used to serve a particular political purpose of another partner, such as promoting a false image that the project has the full support of people with disabilities:

We were only one voice on the board of governors...No matter what you say or what you do, you are always going to be a minority and instead of being in power, you will be disempowered because...well you are part of the decision-making process, so if you're part of the decision-making process in a democratic society, you have to own the majority, and that's the process. ON-LINE DOCUMENT: Ph 3 Pre FABRICIO*43-45.

I considered issues of cooptation, a destructive and yet sometimes insidious force, in my journal entries.

Sometimes there are very powerful forces that manipulate members of a group to go against other members of a group...this kind of sabotage is particularly evident in vulnerable groups of individuals whose self-esteem is volatile, weak and unfed. ON-LINE DOCUMENT: Journal#2 p.28.

People who agree to sit on committees often don't realize the impact of this on the issue -- the message it sends to and from the stakeholder group being represented. ON-LINE DOCUMENT: Journal#2 p.38.
Similar variables may possibly play a role when a disability representative does not agree with the values guiding a partnership group, but finds it difficult to leave or confront the group.

I also found myself confronting issues of cooptation and manipulation while attending a conference devoted to public participation. I was shocked by what I saw as the blatant use of participatory methods in communities for the purposes of placating the public into accepting changes, such as nearby pipelines and nuclear power stations, that would result in financial benefits for large corporations. Although some of the presenters at this corporate sponsored conference were explicitly speaking of manipulating the public, the process as experienced at the community level, would be in the form of hidden manipulation or insidious cooption. Part of this process lies in making individuals feel good about themselves, thus linking the personal to the political.

In my journal, I expressed the discouragement I felt about the role of public participation practitioners in facilitating this process and the greed of corporations. This greed was reflected by one corporate employee involved in organizing the conference, who attempted to extract fees from two volunteer presenters who lived on a fixed disability pension. I wrote, "Just finished attending a conference on public participation -- I'm feeling very cynical about it....I saw it [greed]... all over the place -- from people (independent consultants) exchanging business cards to the conference organizers chasing [us] down for outstanding fees." ON-LINE DOCUMENT: Journal#2 p.25.

My journal entries, including the following, indicate my fear that people with disabilities may be particularly vulnerable to cooptation:

...the nondisability population does this [reinforce status quo] too -- it's part of a larger social environment. For people with disabilities this is exaggerated because some people
with disabilities want to combat the general and common notion that people with disabilities are not worthy/useful etc. In our society the reality is that these positions on committees can lead to future opportunities if not within the disability movement [then] within the nondisability general society or specifically within those structures that attempt to manage and control people with disabilities, e.g., social service, government, a “partner” within a project with a distinctly different view of the world. ON-LINE DOCUMENT: Journal#2 p.29 & 30.

In the following entry I wonder if what I observed and interpreted in one situation might occur elsewhere. I refer to a situation where some disability representatives leave a partnership because of frustration and a lack of satisfaction with the concessions made by other stakeholders, while other representatives remain for personal and possibly ideological reasons. I wondered if a long personal history of oppression would not only lead representatives to set low expectations of equality but also be strongly influenced by perks that may be offered:

...such low expectations because of such a long history of oppression and being stepped on -- or whose self-esteem was so low they thought that this was good because at least they were noticed. And once one group makes a spark the powerful pay more attention to those who remain -- paying them honoraria or compliments. ON-LINE DOCUMENT: Journal #2 p.45.

Although there appeared to be personal reasons for staying, from a larger political perspective, this split was viewed by some as weakening the demands for change that were made by the group that left. Thus the personal aspects of the situation influenced the politics of the partnership.
Representative Responsibilities

What follows in this section are central representation responsibilities to be considered by all of the partners involved in a community partnership. Given that issues related to power sharing and personal needs may interfere with the original goals of representation within a community partnership, it may be helpful to consider solutions alluded to by participants in this study, such as developing a mechanism for accountability, guiding principles, and terms of participation.

Accountability

Accountability at various levels was a significant theme that arose from the data. At one level, there was accountability to one's self. For example, one participant discussed how becoming absorbed in the politics of the disability movement had been a distraction from his connection to a more spiritual part of life. He said, "on a personal level, I kind of got away from the spiritual aspect of life and I find getting caught up in this whole disability political thing can be a little bit...sometimes I feel a little bit like it's not going anywhere." ON-LINE DOCUMENT: Ph 3 Pre GERALD*83.

Accountability was also explored at the level of the organization. The quotation below illustrates how important it was for a representative to attempt to raise issues that affect people with many forms of disability rather than promote the interests of a particular organization.

I don't care if you think you've got the best thing since sliced bread for your organization, you're generic, you're there as a consumer, you're not there as a representative of that association. ON-LINE DOCUMENT: Ph 3 Pre ANNA*264.
Being accountable to an organization was helpful but not necessarily the solution to accountability dilemmas, as was pointed out by one of the participants who expressed some harsh views about some disability organization representatives. He also identified the need for organizations to be accountable to individuals with a disability in the community.

Within the Canadian context, I was a member of several organizations and what I find... is that national organizations are good for nothing...it's like a group of big egos meet together and they praise each other. That's more or less what I think. In terms of what they achieve for the little guy, the little person with disability, not that much. ON-LINE DOCUMENT: Ph3 Pre FABRICIO*146.

As can be expected, accountability arrangements can become problematic when acting on behalf of one party's interests, such as the individual community member with a disability, is in direct conflict with the interests of another, such as the organization or the funder. Several participants of the third workshop began thoughtfully to question issues of representation and accountability.

One of the things I should have known but really stood out for me at the conference [workshop]. There's a person who heads up [a group]...who's a quadriplegic. Does he represent people with disabilities? No [not necessarily]. ON-LINE DOCUMENT: Ph3 Post GERALD*277.

It's a strange thing because she still is an aboriginal woman and has a great deal of knowledge in that area but now they really resent her speaking for them because they didn't ask her [to] nor will they ever know what she said [as their supposed representative]. ON-LINE DOCUMENT: Ph3 Post ANNA*100-102.
This group also discussed in detail a metaphor of making one's own bread from different grains to feed the needs of the people rather than relying on government funding. They articulated their desire for autonomy from the "strings" attached to funds.

Being directly accountable to individuals with disabilities may not be a straightforward task. In my journal, I reflected upon dilemmas of trying to have my work on a past project guided by a particular group of people with disabilities. In this circumstance, I considered it more important to be guided by the group I represented than to take action that I personally thought was more appropriate.

It's not all that simple -- I remember with the [disability project group] trying to be led by people who didn't have the whole picture or as much experience with people [with various forms of disabilities] as I did etc. but ultimately it was their choice and if it collapsed -- it was their collapse -- not me holding it all together on my lap. ON-LINE DOCUMENT: Journal#3 p.85.

Accountability to the funder of a project was also explored in my journal entries. Difficulties it seemed to me, arose when disability representatives attempted to satisfy the interests of the funder at all times, regardless of whether they were presently involved in a funded project, in order to be an attractive recipient of funds in the future. ON-LINE DOCUMENT: Journal#4 p.10.

**Guiding Principles within a Community Partnership**

In additional to the guiding philosophies that each partner might bring to a community partnership, at times the partners may also agree upon a set of principles to guide the work they do together. During the
second workshop, participants explored issues related to the challenges that can arise when two different organizations, Independent Living Centres and Women's Centres come together in a partnership.

A significant difference between the two groups related to the fact that the Independent Living Centres were mandated to conduct individual advocacy and not collective advocacy; the mandate of the women's centres enabled them to engage in both collective and individual advocacy. Some participants recognized that the two groups might have very different ways of responding to an issue given this difference. One participant stated, "The difference between us might lie in the responsibility of either body to carry out our group activities and lobbying or do advocacy." ON-LINE DOCUMENT: Ph 2 Report*102-104. This difference might, for example, affect the types of activities that each partner contributes to the collective effort of addressing a particular community issue.

Another major difference between these two groups was the way in which each group interpreted the need for women to determine what was in their best interests. I discussed this matter in the Community Report that I prepared based on interviews with the participants involved in the second workshop:

Choice: Supporting individual choice and control were common principles to both groups. However, after viewing a videotape on issues of sexuality for women with disabilities, it became apparent during the group discussion that the form and emphasis of individual choice could be very different. Some women's centres were involved in supporting women in choosing to have an abortion, whereas some of the Independent Living Centre's activities were focused on supporting disabled women in choosing to have and raise children. One participant stated, "I think that one thing that came through as a common theme for the two was that choice for women was important...saying from women's centres that...when we talk choice, we were talking either about abortion or not and when disabled women were
talking choice they were talking about whether or not they should [according to others] even have a family." ON-LINE DOCUMENT: Ph 2 Report*121-123.

Through the participants' group discussion in the third workshop, they discerned that there may be pressure to reach consensus on some issues and compromise on others within a partnership. Several spoke of the need to be prepared, with clear limits to compromise, before entering into a final discussion on such matters.

I think if we decide what we would like to see and then say, okay this is what I want but this is what I might settle for -- so whoever is going into this conflict-resolution situation has already determined this is what we really want, but we might settle for this...so we sort of examine all the variables and decide, so that if it happens in the meeting, we're prepared. So we prepare ourselves for compromise. We know what we really want, but [also what] we might settle [for]. ON-LINE DOCUMENT: Ph3D4 CONFLICT*178.

The participants of the third workshop also discussed the value in being aware of one's own contradictions. One of the participants described a workshop follow-up plan that seemed to involve taking personal control over a matter rather than allowing the members being represented to be involved in guiding the process. It became apparent to me, as one of the facilitators, that this topic might warrant a discussion. The plan appeared to be counter to the community development principles and the representation responsibilities that the group had previously emphasized. There was agreement among several participants that contradiction may represent a person's evolving understanding of an issue. Both in-group discussions among people with disabilities and a negotiation situation involving several partners were discussed.
I think all of us, at least me and I think it's true for most of us, one day we'll say something and the next day we'll say something totally different. I don't think...we do it intentionally to be hypocritical, but we are in process...lots of times I'm not even in touch with my own contradictions...I guess through this exercise, I think part of this is saying, hey, there are contradictions in what we say and what we may say and what we may have presented, to try to be in touch with that. Because whenever we're entering into a partnership or negotiating and have to be at least to some degree clear on what our position is, and if we're presenting contradictory information, it does get confusing from the other side, especially when you're in a negotiating situation. But when you're working with, say a group of people with disabilities to try to create your collective position on something, you're going to hear many different perspectives from different people, and even the same person in the same conversation. ON-LINE DOCUMENT: Ph3DY 4 CONTRA/REP*17-25.

**Negotiating Terms of Participation in Partnerships**

Several issues related to setting terms for participation in partnerships were raised in this study. These issues ranged from establishing the terms early and in a manner that included all partners to recognizing circumstances where certain negotiation techniques might work better than others. One participant, for instance, emphasized the importance of establishing the working relationship and terms for participation within community partnerships.

We had to work, first of all on partnership -- how to work together, what we can provide...what are the limits -- but we didn’t do that. It's my mistake...The next time it will be better. ON-LINE DOCUMENT: Ph3 Post BETTY*156.

Another participant stated that he did not like to enter partnerships unless he was able to contribute to setting the terms for participation.
I say to obtain "partnerships" with government...in which they are making the calls -- they set out the priorities -- they set out the guidelines and you have to dance to the rhythm of their band. People like me refuse to do that! If I want to go into a partnership for example with any ministry, the first thing that I would say is, let's sit down together, let's set up our own guidelines and let's decide equally. So then we have not only a say but a decision-making authority when it's coming to consultation, decision making, implementation and evaluation of whatever we're doing together. I don't believe that only some people have the right to decide. ON-LINE DOCUMENT: Ph 3 Pre FABRICIO*47-51.

During another interview, I had presented two contrasting approaches (unilateral and bilateral) taken by participants in the third workshop for establishing terms of participation in partnerships. One participant stated that involving all partners in creating the terms built a sense of ownership and commitment.

KK We were talking about how people can...one approach to partnership agreements is that one party writes it up and prepares it and brings it to another party. Now X talked about her experience of having the other party then respond [to preestablished terms] with some resistance. Like, what's this? Is this a legal document? Where did this come from? Who developed this? And I'm just contrasting that experience, that story, to your story where you talked about how it was a struggle to work on those things. -- it took time, a number of meetings, but over time you developed your own sort of working rules.

I That's right...And because we had developed it together, people respected it. I mean there was a great deal of respect for it and we had things like you're responsible for your own participation. If you can't participate you [need to] share that with others. If you're going to be...We were also dealing with a lot of sensitive issues where people bring baggage around violence and abuse and all of that, all those things had to be worked through. ON-LINE DOCUMENT: Ph3 Post INGRID*206-212.
As another participant pointed out, clarifying responsibilities in writing early in the process of negotiating the partnership may be helpful in the longer term. She said, "because sometimes you're doing a partner thing and you think, did I agree to that? So I think we need to start using them more." ON-LINE DOCUMENT: Ph3 Post EMA*211.

On the first day of the third workshop, the participants identified conditions they believed to be most important for participating in partnerships. Several of their statements describe the type of work that they felt was necessary when establishing terms of the working relationship:

1. Clarity about expectations -- expectations generally, in terms of what working conditions will be and what the amount of time you're expected to spend -- especially time commitment required. Being clear on that.
2. Trust -- you can have the better proposal but if people don't know us...opportunities to build that trust, if you don't know that partner.
3. I'd want to make sure that we have mutual objectives.
4. Having the right support and understanding -- actually what I mean is something there that I need to understand whatever it is to be a good partner...access issues. Also respect.
5. Resources, the human kind and financial kind and all those things to make it happen because you can't create a partnership in a vacuum -- making sure that there are enough resources. Resources, human, financial, all those things to make sure your partnership goes.
6. Commitment.
7. Have the ideas very clear before you enter into any negotiation.
9. Realistic expectations -- attainable goals.
Different styles of negotiating partnerships and the circumstances may lead one to use one approach rather than another, as became apparent in the following dialogue:

KK The approach that's reflected in the partnership agreement framework is a very transparent approach. And the, another approach to negotiating partnerships is...and this has been used for a long time, is that you keep your cards to yourself and you let some information out and you keep some information to yourself...

C And I think, too, depending on who the partners are at the table, you may find that you have to use different methods.

KK Yeah. And in different circumstances. For sure.

C But it would make things a whole lot easier if people would just share all the information they have. ON-LINE DOCUMENT: Ph3 Post CLAUDIA*316-321.

Participants emphasized that, when one was entering into negotiations for a partnership relationship, one should envision the types of benefits that each partner group may be seeking and create opportunities for mutual benefit:

I think we need to look at, too -- we can't just go into a partnership knowing what we want to win from it, we have to go in with a whole set of things that we can offer to our partner where they're going to win too, because if there's no balance of a win/win situation, you're not going to get the partnership to work. I guess a win/win approach to a partnership equals a balance. Mutual benefit. ON-LINE DOCUMENT: Ph3D2 ROLE PLAY*120.
Summary

Within a community partnership, groups of people must be represented by an individual or a few individuals for practical reasons. The political act of representation, however, as discussed in this chapter, requires attention on the part of all partners. In addition, it seems important to note that there are contextual factors related to representation, such as discrimination and power struggles within the "disability community," making the formal role of representation procedures all the more important. When partnerships include people with disabilities it is usually appropriate to provide support; without this support their presence may amount to tokenism. Sharing power was identified as a characteristic of a successful community partnership. This study proposes a link between one's ability to share power and one's ability to be flexible in the way one views him/herself and others. Representation issues appear to be complicated by the personal issues and needs of the individual representative, thus making a less powerful, represented group more susceptible to cooptation and manipulation by other partner groups. This chapter identifies several responsibilities on the part of disability representatives and the collective group that are important to consider within a community partnership.
CHAPTER 6
ACTION AND CHANGE THROUGH PARTNERSHIP

Introduction

In the previous chapters on attitudes and representation, I emphasized the challenges that are involved in community partnerships for the individuals and partner groups. In this chapter, on the other hand, I present some of the positive outcomes of partnerships that participants identified; then, I outline the crucial elements of partnership-building supports that were identified. Within the first section of this chapter I discuss how partnerships may lead to new opportunities for learning, respect, trust, mutual understanding and ultimately new service-delivery methods and community development. In the second section of this chapter, I focus on processes including creating a relaxed atmosphere, developing personal connections, practicing inclusion, using creative learning methods and employing active listening. Supporting a partnership relationship, according to the participants involved in this investigation, also involves understanding similarities and differences among the partner groups and making power explicit. Since the three partnership workshops included in this study were themselves a form of partnership, the data were drawn from comments and observations that were based on direct workshop experience as well as experiences in other partnerships within the participants’ communities.
Positive Outcomes of Partnership

Many positive outcomes may result from community partnership, including those involving interpersonal relationships and those that affect community change. These positive aspects of partnership may provide motivation to people who are interested in using a partnership approach to address a community issue.

Opportunities for New Learning

Many people involved in this study spoke about how they acquired new ideas from their experiences of being involved in partnership projects and partnership workshops. One participant described how she was introduced to new ideas during the second workshop: "When I would listen to things that were said, they were things I had never thought of [before]." ON-LINE DOCUMENT: Ph 2 Report*247. The following quotations illustrate that the partnership-building process and living with a disability were some of the areas of learning.

There were two things for me that really stayed in my head -- one was just the building of partnerships, that whole process, I learned a lot from that. ON-LINE DOCUMENT: Ph 2 Report*244.

I did get something out of it. I think I gained insights that I probably didn't have as to what it is really like to live with a disability. And it did make me start thinking about how things look from a very different perspective. ON-LINE DOCUMENT: Ph 2 Report*64.

The third workshop of this study was designed to examine in depth the central partnership issues that arose from the first two phases of the study. Several participants involved in the third workshop stated that they
found their experience of building a collective knowledge about partnership provided them with new understandings and a sense that their ideas and concerns about partnership based on their individual experiences were valid.

My sense is that many of us had a lot of "ahas" and validation and confirmation as well in terms of our shared lived experience regarding the realities of working in social justice and in the nonprofit [sector] as it relates to programs and services for people with a disability. There were a lot of conversations where people described and shared the challenges and the highlights and I think there were a lot of people who tied right in and said, "yeah I've had that experience, that's very similar in our organization." ON-LINE DOCUMENT: Ph3 Post HELEN*13-15.

The experience of having one's opinions understood, developed and validated appeared to be powerful. This process may be linked to the desire expressed by some disability representatives to have consumer-only meetings at times throughout their community partnership project.

Participants also spoke of the importance of collaborative work and the learning that took place during facilitated and informal interactions with people who were representing other stakeholder groups or organizations.

Part of it that, number one, was just meeting the women, and we also had time for some good social time together, so it was just...meeting the women in a social context. ON-LINE DOCUMENT: Ph 2 - Int O*385.

I came face to face with all kinds of stuff at that meeting, which was really good for me to do, so that was good for me personally and then to take it home and try and describe it to the people here at home. ON-LINE DOCUMENT: Ph 2 Report*241.
In addition to the content issues that would be addressed in collaborative work, people spoke of their growing appreciation for the valuable contribution that each participant brought to the learning experience. The following were statements made during the daily evaluation exercise on the third workshop:

I just again am impressed with the calibre of my co-participants and I really appreciate all the wonderful things that are coming out because you couldn't sit down and come up with all that stuff on your own. ON-LINE DOCUMENT: Ph3D2 EVAL/CLOSE*49.

I hope that we don't get so tired, that we stop enjoying working together and having the humor because it really helps the day go by. And I want to thank you all for being who you are. ON-LINE DOCUMENT: Ph3D2 EVAL/CLOSE*49.

In the following example, a participant described the learning that took place for her through her involvement in a community partnership whose goal was to design and build an apartment complex with wheelchair-accessible units for people with disabilities.

So it was hard sometimes and also the people who were going to be using the building were largely inexperienced in dealing with this kind of partnership so it was a growth experience for a lot of those people and an empowering experience. ON-LINE DOCUMENT: Ph 3 Pre INGRID*87.

Other partnerships were identified as sites for educating business people and government departments.

The... benefit I see is that dealing in a partnership manner with business types and governments makes them more aware of people with disabilities, their needs, and makes
them more aware that people with disabilities are the same as them. They might do things differently, but they're still people. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*402.

Some individuals described how their participation made them feel like they had something of value to contribute. One woman stated, "It makes me -- feel like me, because I know I contributed -- not much, but I did!" ON-LINE DOCUMENT: Ph 1 - Int MO*387. Another participant spoke about educating community members, emphasizing the empowerment that people feel when they are involved in addressing an issue that directly affects them.

Personally, as a person with disability, I will educate our community in community development principles so they could empower themselves, they could come out from where they are now... with a strong voice. I know it's a dream but I know that can be achieved. ON-LINE DOCUMENT: Ph 3 Pre FABRICIO*152.

**Mutual Respect**

One of the participants related how she learned about the importance of respect in partnerships through her involvement with a particular community initiative; she viewed a respectful environment as essential in terms of enabling people to be open to other perspectives.

There's a group that I've been working with for the last five or six years around violence and abuse, and it's a community-based group from a lot of different organizations and a lot of different levels of government and the facilitator for this group was just wonderful in terms of being able to bring, again, everybody's perspective to the table and to get people working together to really bring about some change. And, again, it was a very long-term process, but very respectful. And the respect that the group got over the years for each other and for each other's points of view and all of that, I think has really influenced the way I look at potential partnerships and potential activities. You know, you have to have that and you
can't let one agenda take over, you know you have to respect all the points of view no matter how difficult that is. ON-LINE DOCUMENT: Ph 3 Pre INGRID*108-112.

Although the people involved in the study expressed a variety of visions of partnership, one participant expressed his opinion that respect was the centrepiece of a true partnership: "I don't think it's overstating the case to say that true partnership is built on justice, mutual respect, a love and wanting to...help or encourage other people. And when you have that, you have a true partnership." ON-LINE DOCUMENT: Ph 3 Pre GERALD*274. The importance of the issue of respect also arose during the third workshop, when a small group of participants created a mural that illustrated the "ingredients needed for a good partnership." The spokesperson for the group said, "We kind of looked at disabled people as being the roots which would grow into a nice strong tree [representing partnership], but in order for it to grow, it needed the right environment of respect." ON-LINE DOCUMENT: Ph3D1 MURAL*65.

The issue of respect arose during a role-play exercise in the third workshop. In the follow-up discussion, members of the group identified a variety of ways that disrespect was displayed through body language. In the particular scene as depicted below, a disability representative met a minister of a government department and his ministerial assistant. A participant observed that, "the assistant was not respectful and was impatient and a distraction to the meeting...he was sort of pacing back and forth and looking at his watch." ON-LINE DOCUMENT: Ph3D4 CONFLICT*23.

A positive display of respect was described by another participant involved in the first workshop. She said, "nobody was laughed at, nobody was considered to be -- their opinions to be invalid." ON-LINE DOCUMENT: Ph 1 - Int K0*145. Thus it appears from these examples that having one's ideas heard is an important element of feeling respected.
Several participants spoke about coming to recognize and develop respect for the different ways that people convey their ideas through various forms of communication. One participant emphasized that it was a learning experience to work with people who communicated differently: "people delivered differently and in different manner(s) and in different language(s)...I learned a lot." ON-LINE DOCUMENT: Ph 1 - Int MO*387.

This same issue was articulated from the perspective of a participant who communicated in a manner that he recognized as different from others. In the dialogue that follows I asked what impact he thought his participation may have had on others. What follows are excerpts from our longer discussion:

KK And I was wondering, whether you think that people learned about things because you were involved in the group? Do you think that that was a good experience for them -- think they learned something?
NO Yeah.
KK What do you think that they're learning?
NO Um, try and understand what I was saying.
KK Right, they were learning about trying to understand what you were saying. And they were learning about patience. What else do you think they learned? Did they learn about, um, talking to people, like adults? [a topic raised earlier in interview]
NO Yeah.
KK Even if they speak differently.
NO Yeah. They got to be patient with me, not make fun of me. ON-LINE DOCUMENT: Ph 1 - Int NO*789-799.

The issue of providing access supports in a respectful way was raised by a participant with a disability who requires such support. In the following dialogue, the participant makes clear that respect is a crucial
component of the process of providing the supports needed to accommodate her disability. This participant related her experiences of being talked about as if she was not in the room.

KK It's an important thing... to have... individual [support] partners when you're going to do things and be involved in things -- to support your full participation, right?

E Exactly. And not say, we'll take her here and take her there.

KK So to check it out with you and have you direct -- you're in control. Their role is to support you but not to control you.

E No. Especially when you're sitting in a room and people say, [name] has to be somewhere, we'll take her here and take her there and it's like, hey hey the person is right here! ON-LINE DOCUMENT: Ph3 Post EMA*39-47.

Acknowledging cultural and class difference among members of a partnership were also raised by the people interviewed. The need for partnerships to be inclusive of people who are from different cultures was noted by one participant who described herself as being strongly influenced by the Philippine culture in which she grew up: "There's a need for understanding other cultures -- that they are people too and they have their own beliefs to be respected." ON-LINE DOCUMENT: Ph1 Report*211.

Many of the participants recognized the dominant role of "white people" within the social movements that they were involved in and the need to work to integrate the perspectives of those from different ethnocultural groups. The following quotes were taken from interviews of the second workshop:

It was sort of white middle-class women that were speaking for everybody and trying to improve the situation of these other groups, these other groups are becoming more
empowered all of the time and are speaking out for themselves.....speaking as a white woman we better take a real good look at what in fact we are doing. ON-LINE DOCUMENT: Ph 2 Report*188-197.

If you’re a woman of color and belong to a certain culture and you have a disability and your role in society is viewed as pretty minimal -- taking risks is not something, [that is done easily] like finding a job or housing...feeling comfortable enough to join your church group. ON-LINE DOCUMENT: Ph 2 Report*188-197.

A respectful environment was also discussed in terms of the implications for resolving conflict within a community partnership. As one participant pointed out below, a respectful environment may allow people to agree to disagree and to continue to work on problems until a resolution is found.

When there are different perspectives that are represented -- that at least everybody walks in there with caring and respect and showing respect so that you can get to those points where you can agree to disagree, as opposed to having somebody get up and walk away from the table, or that when a problem does become identified, it doesn’t get seen as your problem -- it’s the problem...that’s facing the whole partnership. ON-LINE DOCUMENT: Ph3D4 CONFLICT*122-126.

**Trust**

Building trust was a theme that arose frequently throughout the study as a positive component and outcome of community partnerships. Trusting one another had several implications for the development of working relationships in partnerships among people who may live and work in different spheres of society. One participant stated the following opinion:
I think that partnerships can be the catalyst for creating the forums to address disability issues where you can take people that wouldn't normally sit down and talk about disability issues and under the formalization of a partnership where they're coming in thinking that they have equality in addressing it, then consumers trust and they trust and I think that gives us the opportunity to start more cooperative activity before we... I know it's trendy too, so we have to be careful of that but I think that's a new opportunity, with all its risks. 

ON-LINE DOCUMENT: Ph3D1 PAF*175-185.

Open communication and respect appear to be important prerequisites for fostering trust and empathy. One participant gave the example of the trust she felt in disclosing information in our interview:

I know I'm going to better understand someone's needs if I know where they're coming from and I know a little bit about them. I think we do need to be prepared to first of all share those experiences and hear what other people's experiences are, be prepared to listen... a whole bunch of trust issues that arise as well at that point... When you speak about yourself personally, for example I talked to you about having some interest at some point in [a particular social movement], right? That's a kind of risk that I take, to share that information with you. Because depending on what your preconceived ideas already are about that movement, you may in fact put some kind of judgment... And basically it boils down to the fact, are we going to be judged because of some... and is that going to affect the way that people respond to us and hear us. 

ON-LINE DOCUMENT: Ph 3 Pre DIANNE*265-275.

In the group discussion during the third workshop, people discussed how some partnerships do not develop because certain individuals will not trust enough to participate in open communication.

I think sometimes getting into a partnership the discussion and the activity relating to getting that partnership up and going sometimes is, you have to reveal too much of who you
are and where you live, to contribute to that partnership, and some people will not do that, they will not take that risk to expose themselves to that level so I think sometimes the risk is too much and they won't play. ON-LINE DOCUMENT: Ph3D1 PAF*133.

One participant spoke about sharing agendas openly: "Well, we all have an agenda and I think the quality of a relationship/partnership is based on the two groups really coming to the point where they can analyze and really be honest about their agendas." ON-LINE DOCUMENT: Ph 3 Pre GERALD*286. Yet another participant articulated how an approach that assumes that partners automatically trust one another could be problematic for her: "You know - 'there's nothing wrong with trusting each other. What's wrong with you guys?'...[this approach] could be a problem!" ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*349.

It appears that trust is built over time through opportunities to observe actions taken by other partner groups and individuals. One participant spoke of building credibility and trust among others:

They have a trust level for us -- like the chief has written us a letter of support for what we have done in the reserve communities because he knows some of the stuff we've done and actually we've been successful in influencing private donations of money for equipment -- things like that. So we've got some check marks beside our name but we really haven't proven ourselves. ON-LINE DOCUMENT: Ph 3 Pre ANNA*398.

**Understanding Each Other's Perspectives**

One of the positive outcomes of successful partnerships identified by several participants was the development of the skills required to understand the perspectives of others.

Several participants with disabilities described their efforts to see issues from a variety of perspectives. One participant reflected on how she
thought people with disabilities might do more to involve people who do not have disabilities but who have been traditionally left out for other reasons.

It's okay for us to look at our own world and see how it doesn't include us as people with disabilities, but the fact of the matter is there are other people in our world who don't feel involved or included in this world either...and we may not be including them. That's one thing as we just said, but more importantly, we might not even have thought of their issues...how do their issues not compete, not even necessarily mesh, but how do we acknowledge them, and recognize them, and see, and find a way of all of our needs being met in this whole world. ON-LINE DOCUMENT: Ph 2 - Int UO*605-613.

Fitting one's own individual perspectives into a broader world view appeared to be important. An approach that acknowledges the perspectives of others was described in a group discussion about conflict resolution by one participant: "Like it's not your problem, it's our problem. Or even agreeing to disagree, if it comes to that...trying to look at it from their point of view, too." ON-LINE DOCUMENT: Ph3D4 CONFLICT*119-124.

Another person mentioned how seeing the perspectives of others does not necessarily mean losing one's own perspective.

Just because people have different points of view doesn't mean there's a right and a wrong. So there are different variations of the truth and sometimes we just look for absolutes, in terms of if I'm right, they must be wrong. ON-LINE DOCUMENT: Ph3 Post JOANNE*17.

This same participant also depicted a situation where the expressed perspectives of another partner resulted in a reshaping of her view of the partnership in which she was involved.
We always felt that the partnership was there for people with disabilities to put together this project and that we were the ones that would get something out of it and one of the other partners said no, that's not it, we all get something out of it. We're not there just to do something for you, we're getting something out of it too, and he explained what everybody else was getting out of it. So it was really good. My perceptions aren't always correct and that others are willing to share theirs. ON-LINE DOCUMENT: Ph3 Post JOANNE*19.

Several participants indicated a need to have power issues acknowledged. For some people, it was important for the specific concerns that they perceived about power differentials to be acknowledged by the other members of a partnership. In the situation that one person described, the individuals involved were not involved in overtly discriminating practices themselves, and yet she spoke of the need to make them aware of the power issues because it affected the way that she saw the world and was treated by others. It therefore influenced the way that she would be comfortable participating in a partnership.

...hear us describe how we like to be in control and stuff like that and that partnerships are hard for us because of the overriding power of other people. They [members of the community partnership] listened intently because it was something new. Because they treat persons with disabilities the same, they assume that everybody does. They assume everybody treats people with disabilities with respect and values their opinion as much as someone else's, but that's not always true. ON-LINE DOCUMENT: Ph3 Post JOANNE*19-21.

**Personal Connections that Foster Mutual Understanding**

The participants identified several benefits that resulted from developing personal connections with the people involved in community
partnerships, ranging from meeting emotional needs and understanding issues in the context of individual lives to developing strategic alliances for future community projects.

One participant talked about the emotional connection that she felt with one of the other participants in the partnership group and emphasized the value of this experience for her.

If you don't really get some time to spend with a person, you don't get to know [that person] -- you don't get to connect to the fact that this is a person. Did you see him [one participant with a disability who does not have an understood method of communication] smile when he left here...he touched me when he was there...he reached me just very briefly...it's amazing...to me it's valuable, it's worth, no money can buy it...I sometimes run out of words to say it, to describe it because it's just something that you cannot explain.

Opinions about the role of emotions in communication varied among participants.

**Understanding the Community Issue in the Context of People's Lives**

Several of the participants spoke of the value of working directly with people who are affected by an issue when developing a solution. This process was thought to place the issue in the context of individuals' lives.

For him, it's real. It's a true to life story.

It was a time to get to know people and to get to know other people who the adult guardianship legislation is going to directly affect.
During the first workshop I observed that the presence of people directly affected by the issue being explored, for example, people potentially affected by changes to the guardianship legislation in the first workshop, facilitated the group's integration of relevant ideas into action planning. I discussed this in the Community Report excerpt below:

In my observation, the presence of people who could be directly affected by the legislation appeared to influence the work of the group, as well as its discussion of issues related to the process and structure of the "agency's" activities within the community. For example, the group dealt with the fact that there were several members who used alternative methods of communication. These considerations were integrated into the discussion about including the "adult" in the process of intervening in a situation of abuse, neglect or self-neglect by providing means for the "adult" to be involved by acknowledging and using alternative communication methods, such as, behavior, sign language or plain language. ON-LINE DOCUMENT: Ph 1 Report*184.

As another participant recounted, working directly with people with disabilities also acknowledges the expertise that they hold based on their lived experience.

Persons with disabilities being the most marginalized group of society... I really believe that, and working with people with disabilities and having a disability myself, using my own experience. I guess I realize that the people are... they're the experts in their own needs. ON-LINE DOCUMENT: Ph 3 Pre CLAUDIA*179.

Two people involved in the third workshop spoke of the value of working with others who are motivated to take action for social change:
There were people [with disabilities] there who were more or less movers and shakers from wherever they come from and they have very powerful staff right there and they were not just having dreams...that they were dealing with. ON-LINE DOCUMENT: Ph3 Post FABRICIO*25.

It was a partnership workshop and I think what stood out for me is I got to know and be aware that there are a lot of people out there who are our partners and the things that they were doing [are] ...different than ours [things] -- it was interesting to explore how they did them. ON-LINE DOCUMENT: Ph3 Post EMA*7-11.

One participant elaborated the many benefits that she experienced as a result of establishing strong interpersonal relationships within a partnership.

It was a very positive experience... the group really grew and grew really close personally through working through all of these issues. Some difficult issues around abuse and violence and what kind of solutions we can put in place to start to address some of them in our communities. But over the course of, again, two or three years, the group really bonded and everybody's gone on to different things now, but remain really close to those people because the working relationship was very positive and very respectful...the relationships that I built [were] in the areas that I normally wouldn't have interacted. For example, in the formal justice system and with the enforcement officials and those kinds of relationships are valuable ones to me now because I know I can call on somebody if I need information or anything like that, on the basis of that working relationship that we established. ON-LINE DOCUMENT: Ph 3 Pre INGRID*116-119 & 158-163.

The value of building interpersonal connections was a theme that arose in interviews and during my observations from the first two workshops. As a result, efforts were made to provide opportunities for connections to be built among the men and women involved in the third
workshop. The importance that the participants from the third workshop placed on connections was clear from the following interview dialogue:

KK I wonder if you can describe the workshop and what stood out for you.
H I have lots of images about the workshop. The thing that stands out the most is the relationship between the process and the connection that I was able to make with the group participants. And I think the two were quite closely related...the way that the days were structured and the opportunities that we had to work together in different ways - the small group and then the larger group -- I think allowed people an opportunity to establish some relationships. ON-LINE DOCUMENT: Ph3 Post HELEN*5-9.

**Challenging Attitudes**

Participants described the opportunities for challenging attitudes and therefore the nature of interpersonal interactions within community partnerships. One participant talked about assumptions and behavior in the following way:

It's just a different attitude, different way of speaking to you, the avoidance of you, the assumption that you're not as intelligent as the person standing beside you. ON-LINE DOCUMENT: Ph 3 Pre ANNA*65.

One nondisabled woman involved in the second partnership workshop spoke of the learning that took place for her when she spent time informally with partners who had disabilities. She directly witnessed inaccessibility in everyday life activities.

Actually I did get something out of it [the workshop]....it did make me start thinking about how things look from a very different perspective. A very concrete example because it still
sticks in my mind and it was the issue of outdoor steps and wheelchairs. Now, I realize most public places these days have wheelchair ramps etc. but I also happened to notice that there were several drug stores and small stores on the street between the hotel and where the workshop was being held that had maybe a three-inch door step or door sill that friends I was with simply couldn’t get into the drug store because of the three-inch door sill. I look for that kind of thing [now]. ON-LINE DOCUMENT: Ph 2 - Int SO*318-330.

Evidence of challenging one’s own stereotype and examining those of others existed in the participants' comments. In one participant's opinion, a comfortable atmosphere played an important role in allowing partners to check the assumptions made by themselves and others:

Whenever you enter into a partnership relationship all of a sudden people have to take a step back and allow a whole other set of assumptions to become visible although the great thing about this process was that as things became more visible everyone maintained a very high level of comfort and that was very obvious. ON-LINE DOCUMENT: Ph 2 - Int PO*105.

Some participants discussed the nature of stereotypes and their efforts to confront their own beliefs. One nondisabled woman spoke about how she came to challenge her own beliefs about disability as something that is necessarily visible.

It was the most time I'd ever spent around women with various disabilities, I mean there were some women I was looking at, it was, "I know you're representing an Independent Living Centre but I can't see what's wrong with you." and I was thinking of all my own stereotypes. ON-LINE DOCUMENT: Ph 2 Report*60.

A woman who had a disability described how she came to understand that even though she had one negative experience with a nondisabled
person, that she was not going to judge all nondisabled people based on this.

If people are nice and accepting towards you all your life and all of a sudden you go somewhere and you meet people that aren’t, it’s a slap in the face. But you can’t judge everyone by that one person. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*336.

One participant spoke about how her interaction with people with disabilities during the second partnership workshop resulted in a different way of viewing the world.

I think I gained insights that I probably didn’t have as to what it is really like to live with a disability. And it did make me start thinking about how things look from a very different perspective. ON-LINE DOCUMENT: Ph 2 Report*67.

**New Service Delivery Models and Community Development**

A central purpose of a community partnership is to address issues such as the provision of community services or interventions that are of common concern to all of the partner groups involved. Designing and implementing a new service delivery model can be facilitated by developing a comprehensive understanding of the service needs to be targeted, the people involved and the setting. Several participants indicated that they found a collaborative approach helpful in terms of developing a more comprehensive understanding of the issues involved. In the following quotation, a service provider indicates that a collaborative approach was helpful in defining the central issues.
Defining abuse [the topic of the first workshop]. Identifying people who are at risk for abuse, neglect...It was a time to get to know people and to get to know other people who the adult guardianship legislation is going to directly affect. It was a learning experience. ON-LINE DOCUMENT: Ph 1 - Int KO*132-133.

Another participant emphasized the importance of a collaborative approach in developing a clearer understanding of the actions needed to address the community issue.

You could say [there were] diverse sides of the problem that we were trying to resolve. And because they're at different levels in the system in the project, that you have there the different concerns at different levels...And that really is the best way to get a consensus of what the problems really are and how to resolve them or at least start to resolve them. ON-LINE DOCUMENT: Ph 1 - Int LO*917-918.

In the Community Report for the first workshop, I discussed how participants developed a more thorough understanding of the complex issues involved and how they might affect the process of taking action within a particular community context.

As a result of the project, issues related to a community response to abuse, neglect, and self-neglect were seen in a more comprehensive manner. This was described by one participant as "well, the grey areas have now become more grey." I believe this is a natural response in a situation where people have just completed a week-long effort to understand difficult issues from multiple perspectives. A comprehensive approach became seen as neither simple nor narrow. Another participant described her view of the issues after the workshop as follows, "it's an incredible thing that someone would have an influence or an effect on whether someone [else] is going to be cared for properly -- whether they're going to be cared for or whether they have the ability to make their own decisions -- it's an issue that needs to really really be carefully looked at -- so that the best will happen for each person involved."
The workshop played an essential role in assisting community members in identifying these complexities. In my opinion, while it may be uncomfortable to simultaneously carry differing views and decipher multiple layers of reality, this is a necessary step in the process of designing a response that would meet the needs of the community in a manner that acknowledges and integrates elements of social, economic and political realities. ON-LINE DOCUMENT: Ph 1 Report*154-158.

One participant who represented seniors' issues in the first workshop conveyed the importance he saw of involving many different stakeholders in the development and implementation of community services.

You have the people who plan, the people who give directives, and the people who do. I think in any type of community you all have to work together because if you don’t it doesn’t happen. The manager can’t do without the people who either run the computers or wait at the counter...they all have special abilities to do their jobs...everyone is needed on different levels. And it gives a good representation of whatever is happening in the community...you have people who are...seeing the problem to be resolved from a different aspect and really I think that’s part of the resolution of problems -- being able to look at it from all sides. ON-LINE DOCUMENT: Ph 1 - Int LO* 941-943.

In the following excerpt from a dialogue during the third workshop, one participant expressed her opinion about the impact of community partnerships on the services that are provided to people with disabilities.

I think one of the benefits of a healthy partnership is the development of new services to meet needs that are not being met by mainstream... service system...New services, new ideas, new ways of doing things... I think that partnerships can be the catalyst for creating the forums to address disability issues. ON-LINE DOCUMENT: Ph3D1 PAF*175-185.
Community development involves linking people to community issues and processes of change. One participant spoke about fostering a sense of belonging to a community as a benefit of being involved in a partnership.

There will be the goal towards achieving a project...Many people will join and make it easier for the benefit of other people. And also they will feel respected and in such a way, their own values would come out and be recognized so that they can become part of the community. ON-LINE DOCUMENT: Ph 1 - Int MO*47.

Many activities of nonprofit organizations can have an impact upon the way individuals live in their community. As shown in the quotation below, one participant depicted the impact that the partnership workshop experience had upon her view of her organization's community development work.

When I think of our own women's centre... like when we say that we try and be accessible...but then when I would listen to things that were said in [the workshop], the things that we had never thought of. I was thinking of the transition houses when...someone was talking about well, what if a woman's got to leave, is there any kind of vehicle, depending on the disability that she could actually be transported from her home? That's not something that -- that's ever entered my mind. And as I said...there were things that were said that should have been obvious to me, and they weren't. So, it was really good to hear...is there any kind of transportation in your community that can get a woman out of the house, and I said, Christ, no there isn't, and they never even thought of anything like that, so it was when we got down to the nitty gritty stuff that I thought it was fabulous. ON-LINE DOCUMENT: Ph 2 - Int TO*385 &393.

One benefit that was expressed within the interviews, was that useful linkages were developed through partnerships. For example, one participant
involved in the second workshop stated, "I made a good connection with someone from [the women's centre] in my area and that was very exciting." ON-LINE DOCUMENT: Ph 2 Report*244. Other study participants described how working relationships developed in the context of one community partnership carried over to new efforts to address other issues. This was exemplified by the following statement:

I think one of the biggest benefits of successful partnership or a good partnership is it creates the opportunity for further partnerships, or among one or more of the partners already at the table and probably taking in new partner, but additional partnerships to address other issues or work on. ON-LINE DOCUMENT: PH3D1 PAF*207.

From the opinions expressed by participants, community development appears to encompass many forms of change that take place at personal, organizational, community and societal levels.

**Supporting Partnership**

People involved in this study discussed several ways that community partnerships might be supported, including establishing a relaxed environment where differences are respected and reflected in the use of a variety of creative learning methods. Participants also spoke of the importance of developing personal connections, using active listening, challenging attitudes, and understanding similarities as well as differences among the partner groups involved. The issue of making explicit the power differences among and within the partner groups was addressed.
Relaxed Atmosphere

As the quotation below illustrates, a comfortable atmosphere within a partnership was found to be conducive to open sharing, reflection and increased participation.

Because of the participants, there was a very natural comfort level that was developed very quickly and I think that people were respected for their opinions and so therefore were very open and willing to share their opinions...there was a very natural respect for everybody's opinion, even if you thought it was a little unusual or different from yours, you respected the fact that it was their opinion and you gave it some thought. I think the comfort level was there and I think you found that particularly with T because I think in another setting, she would have been far more reluctant to express her opinions or speak out or she may in fact have felt somewhat intimidated and that didn't happen, which is a really big compliment for the way the dynamics in that workshop were working. ON-LINE DOCUMENT: Ph3 Post ANNA*55-57.

A participant from the first workshop related what a relaxed atmosphere meant to her.

The facilitator[s] did a really good job of including everybody in the meetings. It was friendly. The geography of the place was conducive towards a very warm atmosphere...There was a small circle, it broke up into small groups, had a great opportunity for interaction. People introduced themselves -- they were addressed by name. ON-LINE DOCUMENT: Ph 1 Report*218.

A relaxed atmosphere was one factor that people identified as conducive to a positive partnership. In fact, for some participants, a relaxed atmosphere as part of the process of working together was more important than concrete outcomes. Said one participant,
It's funny, we just have to relax and you know, take it easy, because if you're so tense it's always the end result that you are looking [at], not how to get there. ON-LINE DOCUMENT: Ph 1 - Int MO*255.

Creating a relaxed atmosphere appeared to increase some people's level of participation. One participant stated in his interview that the relaxed setting of the workshop allowed him to be more physically comfortable, since he often shakes uncontrollably when he is nervous. ON-LINE DOCUMENT: Ph 1- Int NO*415-439. Another participant discussed how he viewed the impact of a relaxed atmosphere on another participant's level of voluntary participation.

Sincerity...I think really it pervades a group, a room...if it's there...Normally, our society is even today...anybody who has a disability [mental health disability] like G's is normally...watched or something like that. But he would share...with us. I mean it shows that he must have felt really comfortable. ON-LINE DOCUMENT: Ph 1 - Int LO*676-760.

**Active Listening and Sharing Personal Stories**

Active listening involves being fully attentive to what a person is communicating and the relevancy that these efforts have for creating understandings that contribute to a group's work. As illustrated below, this can include listening and deriving meaning from personal stories or metaphors.

Lessons in the area of communication styles were significant for me, as I stated in the Community Report for the first workshop in a section I entitled Ways of Listening - Ways of Learning. "One of the most interesting things that I learned from this group...was the extent to which differences occur in people's approaches to communication, teaching and learning. The comments made in interviews illustrate perceived differences in
the role of emotion in learning, indirect versus direct information sharing, and emphasis on process versus outcome of group work." ON-LINE DOCUMENT: Ph 1 Report*225-235.

The following quotation reflects some of the perceptions of one participant about the importance of taking the time to actively listen and become emotionally involved. She contrasted this approach with one that expects direct communication of information in a timely manner (she was referring to a person who has a disability affecting speech, cognition and physical mobility to the extent that any communication efforts were difficult to discern):

A good example is W [a particular participant]. You have to really listen carefully for you to understand her. See all these people, they just don't have time and that is really very sad. Because you cannot get a right answer for the person concerned if you don't listen -- listening is an art... [Some people] don't have time to listen to this "petty" thing, because [the emphasis] is more on the business than feeling. I think we have to look into that. It's not written in words or something -- its just [there] to feel. ON-LINE DOCUMENT: Ph 1 Report*225-235.

Another woman spoke of the importance of taking more time to listen to others. When listening incorporates patience more meaning can be gathered, for instance, when language is being translated into American Sign Language:

Because it has to be controlled so that they can keep the communication being translated, so you have to sit back and listen to someone's whole topic, you can't jump in, so I think keeping all those things in mind, that's the kind of meetings we should set up when we're going to do conflict resolution, and we don't always take the time to do that. ON-LINE DOCUMENT: Ph3D4 CONFLICT*280-282.
When people work together in a partnership, each brings a set of personal experiences that may be relevant to the collective work. Sharing personal stories in a safe and receptive environment was observed to be a valuable form of building understanding during the partnership workshops.

One participant with a disability who participated in the first workshop shared a relevant story of verbal abuse he had encountered.

NO This scary guy ...?...get at me, and grabbed me, and asked questions at me. And making fun of me...They were pretending that they were a cop...and asking for money. Then one of the girls here stopped and told them off. Yeah and he made fun of my ...

KK He made fun of you?

NO Yeah. Way I talk.

KK The way you talk... Right. So you're telling me this story because it's an example of abuse, right, and that was the topic you were saying at the workshop. ON-LINE DOCUMENT: Ph 1 - Int NO*1971-2027.

Another participant stated that, during the first workshop, her understanding grew of the personal impact and issues involved in guardianship for people who are assessed as incapable of making their own decisions.

Sometimes it just really blows my mind to think that can possibly even happen. You know whether it's for an adult or for a child. That's...putting a lot on a judge or the court system...[In] some ways I don't know if it's even right. I mean I know that it has to happen but...it just seems like for one person or a couple of people to have that right to decide [for another person] you know just such a big responsibility. ON-LINE DOCUMENT: Ph 1 - Int OO*1007.
Some individuals may prefer to communicate their ideas through metaphor. This indirect method of conveying information is not always recognized in Western societies where people are often expected to be very direct in communicating ideas. The best example of sharing through metaphor took place during the follow-up meeting after the first workshop. As mentioned in previous chapters, one participant repeated a metaphor to the group without providing an explicit explanation of its relevance to the group discussion. From my perspective as a participant observer at the meeting, I was curious because I did not understand what she was trying to communicate. I was struggling to understand how her story related to the previous discussion regarding forming a core group. I observed that others seemed frustrated, confused or even somewhat irritated about the amount of time she was taking in telling her story that appeared irrelevant. What follows is part of a discussion that I had with this participant after the workshop and follow-up meeting:

KK  But you know... it may be a cultural difference and also a personal difference in the way of communicating. I think some people are used to getting straight to the point. you know, like (a particular participant), for example.

MO  Yes, I know. I observed that...I really noticed it.

KK  So, I'm not sure people do have the practice of getting information from stories and indirectly -- making sense of it.

MO  Well, because I belong to the old school...I said to myself maybe because I don't want directly to hurt people like that if I can say the other way then [I'm] not hurting [anyone directly]...that's my nature. I think that's also my husband's nature. He doesn't want to say it like that, straight to the point, yet he is Canadian...Maybe...my upbringing influenced me.
KK Yes. I'm just hoping that people can, it's like people have to learn. Maybe we should have talked about that in the group, there are other ways of communicating and when other people communicate in this kind of way over here, and you're used to really direct communication, you've got to learn to listen in a different way too, because you have to work on getting the meaning. This person is not going to give it to you.

Practicing Inclusion: Providing Access for People with Disabilities

Many participants spoke about the importance of having all partners acknowledge and act on their responsibility for ensuring that participation in the collective work was accessible for all people. This included overcoming one's fear of approaching people who are different, using plain language and a willingness to provide specific forms of assistance under the direction of the person with a disability receiving the accommodation.

A few participants spoke about overcoming reluctance toward approaching someone with a disability. One participant shared how she initially felt intimidated by one participant who had a disability affecting communication, cognition and mobility. Over time this participant felt more comfortable approaching people who communicated differently. In the second quotation below she described how she later approached another participant who used sign language to communicate.

It's funny you know...I felt intimidated by T at first...and then for the rest of the time...[I] just went up and...interact[ed] with him.

I didn't find it very hard to communicate [with a participant who used sign language]...I just thought, gee...all you have to do is just, you know, take a little initiative and go up and talk to her.
Participation and inclusion from the perspective of someone with a disability affecting cognition and communication was depicted by one participant in the following way:

I couldn’t know when to talk. I didn’t know when to butt in and when not to...I don’t know when to...to butt in...I didn’t know what to say...when we were all together [in a large group]. ON-LINE DOCUMENT: Ph 1 - Int NO*1132-1156.

This participant received one-to-one support to facilitate his participation in a small group. As the support person, I translated the concepts that were raised by others into concrete examples to assist him in understanding. I also facilitated a process of making his personal stories relevant for others to consider.

Although using plain language supports the inclusion of some people with disabilities, it also facilitates the participation of others who may or may not have a disability. The importance of using plain language was emphasized by those participants whose first language was not English.

B I couldn’t understand all the things, because people spoke too fast for me, except PO [a participant with a learning-related disability]. I am like people who has learning difficulty because it [English] is not my language.

KK Plain language is also accessible for people who have English as their second language. ON-LINE DOCUMENT: Ph3 Post BETTY*9-11.

Other people identified what they learned about themselves and how they would work differently in the future as a result of working in a group that included someone who required plain language.
The most demonstrative episode for that whole concept was when Ema was explaining her partnership and Betty said, you know what, this is the first time I have understood every word. And I laughed, laughing at us, ourselves, for getting so caught up in our verbosity, in our choice of words, in the way we express ourselves so that we look intelligent, or we got into the habit of speaking in a certain way. All of that stuff comes into play. And I laughed because that was so true and it was about all of us. But Ema just speaks plainly and clearly and Betty got every single word. ON-LINE DOCUMENT: Ph3 Post ANNA*69.

I've never been present during whisper translation [before the workshop]. And as a facilitator and trainer myself, it was a really great opportunity to see how that [works]...in terms of the diverse needs of different group participants...how that would play into group process. ON-LINE DOCUMENT: Ph3 Post HELEN*17.

Offering and receiving support requires a delicate balance. As discussed in previous sections of the thesis, offering and receiving support presents challenges since it may represent a power imbalance (see "Consumer Control in Partnerships" in Chapter 4). I explored in the following dialogue with a participant of the third workshop, the experience of receiving support through a buddy system:

KK How did you feel about the group at the workshop, because before the workshop you talked a bit about other workshops that you'd been to and you were a bit concerned about making sure that the group understood how to support you and that you wanted to feel included in stuff. How did it go for you?

E Actually it went very well. When D [her designated buddy or assistant] wasn't around, there was someone who came up and said, I'm going to sit beside you. I found that was really good because normally I don't have that. Normally when I'm participating in a workshop, I don't have sometimes someone there doing whisper translation, if I don't understand something. That worked really well and people wanting to learn from me was really interesting. There are always people that are around that say, how am I
supposed to help her? And they're scared to get up and ask a person, to ask them if they need assistance.

KK I thought that it was very effective the way that you presented it to the group because you said, this is a great opportunity, you can learn from me, and then everybody wanted to try it.

E And I thought that was neat. I was really pleased that they did include me and that made me want to try to help them, and they were really helpful.

ON-LINE DOCUMENT: Ph3 Post EMA*49-59.

The buddy system was originally introduced to the planning of the workshop as a way to ensure that this participant, who has a disability affecting learning and vision, might have the assistance that would facilitate her full participation in the workshop. We decided to extend the concept to all participants by starting the workshop in pairs. In the interviews, I decided to explore the issue of providing a buddy system from various perspectives: the person for whom the assistance was to be provided and the provider.

KK And the buddy system, how did that work for you?
E That was good, the buddy was good. I was comfortable and I didn't feel like, if I needed anything I didn't feel I had to go run around asking for whoever, so that went really well.

KK Did it make a difference at all that everybody had a buddy?
E Yeah, it did, because then the person doesn't feel like I'm the only person who needs a buddy. Maybe they won't want to do nothing with me. The other people won't want to do anything with me because I need a buddy and you know, they're going to feel like they're going to have to do some extra work.

KK I think that everybody was learning how to support each other and be supported. And I think there was a lot of shifting around, too. Sometimes it was you and Dianne and sometimes it was me and you or Gerald and you or whatever.
Even though I know that Dianne was there but it's hard for them to do if they have to do the whole day and, you know, whisper translation can be hard on one person's throat. ON-LINE DOCUMENT: Ph3 Post EMA*259-269.

The person who was designated as the buddy prior to the workshop emphasized her perception that gaps among the participants were bridged as a result of their involvement in also providing support.

I think it was really important for both us to have been there and I think there was a lot of learning that went on by other people as a result of it. And I just think the fact that because the two of us had the opportunity to be there... and one of the reasons why I say that is because there's such a split across this country in terms of the organizations that represent and serve people with physical disabilities and the organizations that represent and serve people with mental handicaps...I thought that...we were able to bridge that gap somehow...I was really pleased to see, as the days progressed on, more and more people were willing and wanting to get involved, right? Whether it be doing some whisper translation or being attentive to the fact of what Ema's needs were to participate. So it was great...It just made all the theory so much more real. ON-LINE DOCUMENT: Ph3 Post DIANNE*36-41.

A Variety of Creative Learning Methods

An openness to using a variety of creative learning methods became an important theme in this study. It became apparent that the use of such methods provided rich learning opportunities that were accessible to a range of people regardless of difference due to disability, learning style or personality. Several participants involved in the third workshop that incorporated the use of such methods described how these methods allowed the expression of creative intellectual potential.

As an observer during the first two workshops, it became clear to me that people had varying ways of expressing themselves, obtaining
information and creating understanding. Using a variety of creative learning methods increased learning opportunities for many of the people involved in these partnerships. The issue of accommodating disability and different learning styles was described in the following manner within the Community Report that I prepared based on the first workshop:

The information about the legislation itself was complex, particularly for people who did not have much experience dealing with or reviewing this type of information. Efforts were made during the workshop to use alternative or supplementary methods of learning and presenting information to make it more accessible to all participants. For example, role play was used to illustrate concepts, and plain language interpretation was provided with concrete examples given. ON-LINE DOCUMENT: Ph 1 Report*162.

The impact of having drama as part of the learning process was seen by others to have had a positive impact on the level of participation of some members of the group.

...[T]hat woman [a participant with a disability affecting learning and vision]... I saw her the first day. She was more or less depending on [the other woman who was her buddy]. After that role play, wow! "I am here!" she was saying, I have something to report today for your benefit, people. You don't want to...patronize me, I want to make my person noticed...the action in the role playing -- she took over...and that was one thing that really impressed me...I think it was the process...She felt great about that. And it was an experience for me too. ON-LINE DOCUMENT: Ph3 Post FABRICIO*77-81.

On occasion, participants spoke of modifications that were required in the learning environment to accommodate their disabilities. For example, one participant discussed the impact of group size:
I'm probably more comfortable in a small group because of my hearing than I would be in a large group. Like sometimes when you break into small groups you have ten and twelve people in a small group...and it's easier for me to miss things because of my hearing impairment. So I'm small groups.  

ON-LINE DOCUMENT: Ph3 Post CLAUDIA*147.

Another participant spoke about how information was provided in a verbal format to accommodate her visual impairment.

So I think we were pretty 'on' in terms of how the group gelled. I think, certainly in terms of addressing alternate format and having things spoken aloud [an accommodation for this participant who had a disability affecting vision] and...certainly I felt my needs were met in terms of not only the learning modality.  

ON-LINE DOCUMENT: Ph3 Post HELEN*45.

The need to accommodate differences in terms of learning styles was specifically discussed by several participants. One participant, who used English as her second language, expressed her desire for using drama as a learning tool within the workshop group: "I love acting. I said, give me a skit and I will be the one to do [it]...through action, because...that's the only way I can express my feelings."  

ON-LINE DOCUMENT: Ph 1 - Int MO*277.

Another participant, who has a disability affecting learning, described the use of drama as follows:

That [role play] was interesting. I really enjoyed that. That was good because that is something I'm really good at and I was comfortable with. I think it breaks up too, so you can get the point across.  

ON-LINE DOCUMENT: Ph3 Post EMA*19-31.
Modifying activities so as to accommodate individual levels of comfort was also discussed by some individuals. Although some participants enjoyed the drama or role play as part of the learning environment in partnership workshops, others did not. When asked about her choice not to present her small group's role play to the larger group, a participant stated, “As far as role playing itself, I personally have never been comfortable with it. I don't like it." ON-LINE DOCUMENT: Ph3 Post CLAUDIA*129-143.

Another participant who had reservations about participating in drama stated that she believed that it is important to accommodate different learning styles by providing different types of learning experiences including role play. When reflecting on the workshop experience, she made the following comment:

I understand the benefit of that kind of learning...that's just a perfect example of how you can't stick to one kind of thing and meet the needs of everybody who is trying to learn something...So that's just an enhancement and a verification of the fact that you need a variety of ways to learn. Particularly when you're doing four days. ON-LINE DOCUMENT: Ph3 Post ANNA*49-51.

Several participants spoke about how using a variety of creative learning activities in a group that is conducting collective work unleashes creative intellectual potential. One participant described how role play assisted her in learning more about the topic of partnerships during the third workshop.
I really enjoyed the role play...I've been in partnerships where it feels like there's so much going on and it's helpful to see all the things that influence that, so I found that helpful -- clearing things up. ON-LINE DOCUMENT: Ph3D2 EVAL/CLOSE*25.

While reflecting on her experience of attempting to use creative activities in different settings, another participant told how such activities may be viewed as frivolous by others.

There is a huge creative potential in all of us and I think sometimes it comes out just with the flip charts and the markers and being able to draw and do things in different colors... like the mural was...those kinds of things...great ideas. But it also challenges people because we're rarely invited to express ourselves in that way. "It's not objective, it's not formal, it's not standardized... you know, it doesn't meet the criteria...it's silly really, the untapped potential in people...it just blows me away. ON-LINE DOCUMENT: Ph3 Post HELEN*63-65.

The interviews and transcribed interactions during the third workshop documented the experiences and beliefs of participants with respect to creative learning experiences. What follows is a description of one activity and how it was viewed throughout the process from a variety of perspectives. This activity was introduced on the first day before people knew one another very well. It was intended to draw out, in a comfortable way, what people knew about partnerships. It was introduced in the following manner:

So what we would like to do, we're going to give out one toy to each small group and ask you to talk about, how is this toy like a partnership, or how is it not like a partnership, and we'll give them out to you now so you have lots of time to think about it before it comes up in the afternoon. ON-LINE DOCUMENT: Ph3D1 TALK DRAMA*15.
Later, the paired participants supported one another in reporting back to the larger group. Their reports included personal stories, scenarios, analogies and advice for others. One participant described how a large toy pencil was like a partnership:

It looks like a big stick in that the idea might be that there's too much control in the object itself, that there wouldn't be the sharing of power and control in this partnership because it's just so big. And...the eraser too is so that we can do conflict resolution in a proactive manner so that we can have this available at all times to make sure that we can erase the conflict as we see it growing before it gets to the point where it's going to destroy the partnership. ON-LINE DOCUMENT: Ph3D2 TOYS*110.

At the end of the group activity, I responded to what I heard by saying, "You did great. It is amazing when you hear the stories and all the thought that's been going into looking at this one object and thinking through all the stuff about partnerships - that they can be wrong, or that they're short-lived, all these things that come up" (ON-LINE DOCUMENT: Ph3D2 TOYS*140).

During the activity, the participant who gave the object report as described above stated, "Everybody's got that little creative thing right back here [pointing to the back of her head], that never gets out. This is fun!" ON-LINE DOCUMENT: Ph3D2 TOYS*136. Later, in an interview she elaborated on her views.

I thought those kinds of exercises really make you stretch your thinking on what you're doing because I think when we go into something as cumbersome and serious as looking at the policy for developing a partnership, we don't stop and stretch our minds, to put our heads around all the parameters of what is partnership. That was very beneficial because I think some of those points were, just gave you a fresh new way of looking at things so you're not just looking at going straight forward, you're always looking side to side to see if
there's something you're missing that should be pulled in. ON-LINE DOCUMENT: Ph3 Post ANNA*27-29.

Other comments made about the use of a variety of creative activities to facilitate learning included the following:

I really enjoyed doing the mural because it made you think, it made you think what kind of roles different people play and stuff like that. ON-LINE DOCUMENT: Ph3 Post JOANNE*11.

It is the variety itself that keeps you going because in four days of training, if you had just straight talking, it doesn't sink in all the time, you just get overloaded...if you change the variety, then it keeps your mind, it gives your mind a fresh approach so that you can understand and you can learn, even when your mind gets tired. ON-LINE DOCUMENT: Ph3 Post ANNA*45-47.

A few people indicated in their postworkshop interviews that their views about using a variety of learning methods had changed as a result of participating in the third workshop:

I thought it [the workshop] was excellent. I thought it was very creative. Until that workshop I used to kind of think that stuff was kind of silly, you know, like kindergarten stuff, but I think it was quite creative and I learned a lot through that. ON-LINE DOCUMENT: Ph3 Post GERALD*25-27.

I think we need to use that more often. I know people...people get really shy and intimidated when they look at role plays but I guess we need to find a way so that they become less threatening for people, you know? ON-LINE DOCUMENT: Ph3 Post DIANNE*119.
One participant, who believed strongly in the value of creative learning processes stated,

In the general...we don't have permission to be creative. We don't have permission to use every part of ourselves in the jobs that we do. We are supposed to focus our attention cognitively and that's it. And there are one or two accepted ways of sharing information and of expressing one's self and our ideas and opinions and you just don't cross those lines.

**Making Partner Similarities and Differences Explicit in Order to Develop a Common Vision**

It became apparent that making explicit the similarities and differences among partner groups was very important since they would impact on what and how collective work would be done. This theme was highlighted in the second workshop when women from Women's Centres and women from Independent Living Centres were brought together to consider working in partnership to address common concerns. What follows are quotations taken from follow-up interviews in which the participants reflected on their future ability to work together. They illustrated ideas such as the ability to perceive similarities and differences, the value of common goals, the implications of differences on action, and the importance of developing a common vision of a partnership relationship.

One participant, who is active in the work of Independent Living Centres, found that she had a tendency to focus on the commonalities between the two partner groups:
I don't remember the differences actually. That's interesting. I just remember there were really a lot of similarities and I wasn't surprised by that. I think I'm one that sort of likes to build on what we have in common. ON-LINE DOCUMENT: Ph 2 - Int RO*186.

Another participant, who worked at a Women's Centre, conveyed the importance that she placed on collaboration in situations where two groups shared common goals.

SO Well, actually on a theoretical level, I think it is almost essential that they do come together somehow because the two movements have a lot of common goals and if organizations like ours are to work effectively with women with disabilities, then we do need to work together.

KK So, I guess that's a real strength and if we can come together as two movements we can support one another in achieving our joint goals. Is that what you're saying?

SO Yeah. Because I think it's two very large segments of the Canadian population that have both been marginalized for different reasons but they've still been sort of shuffled to the sidelines and there is strength in numbers. ON-LINE DOCUMENT: Ph 2 - Int SO*366-370.

While reflecting on the experience of exploring and building partnership during the second workshop, participants also related their opinions about having common principles and philosophical approaches.

I think, to me the most common similarities is the fact that women, or people with disability are creating what they feel they need, and are taking charge of providing and delivering those services...and that to me is a very strong commonality, that would take a lot to shake me from wanting to pursue partnership, you know, like it's so important to have that common base, I can almost handle almost anything...and therefore that the power base lies in that grassroots organizing. ON-LINE DOCUMENT: Ph 2 - Int UO*359-375.
The strengths [of a partnership between the Women’s Centres and Independent Living Centres] are in that I see the similarities in philosophies and the fact that, you know, we don’t have to argue that these women or the person with a disability [should be] having control over their own lives. ON-LINE DOCUMENT: Ph 2 Report*97.

One participant who had a disability and worked at an Independent Living Centre gave her views about the advantages of working with a similar partner:

I think of all the places that we would want to have a partnership -- women's centres or women's organizations are closer to our philosophy and would be easiest to amalgamate together in terms of philosophy and providing service. I mean that’s what we found with our program, is that, you know, there’s no question about what we’ve said, in terms of how we believe people with disabilities have a right to this information, to services, to making mistakes, to making decisions, to doing all of that kind of thing. ON-LINE DOCUMENT: Ph 2 - Int QO*975.

It was found that understanding differences among partner groups had important implications for the contributions made and actions taken. During the second workshop, differences between the two partner groups were explored. One participant articulated how she saw the discussion influenced the views of nondisabled women; she referred to the struggle of many disabled women to have the choice to give birth to and raise children and the common practice of aborting fetuses with disabilities.

...[I learned to] not promote abortion as the only option -- the choice issue I think was the common ground issue...the uniqueness that developed...is...who has the capacity to be a parent, and who/what is considered to be a viable worthwhile human being to be birthed...
it opened people's minds and ideas to. geez...this isn't as simple as I thought...it is a pretty touchy topic. ON-LINE DOCUMENT: Ph 2 - Int UO* 319-339.

The form of advocacy that was mandated by the two partner groups presented another significant difference in terms of the form of action that could be taken by each. Although Women's Centres articulated their emphasis on collective political advocacy, the representatives from the Independent Living Centres clarified their mandate to conduct individual advocacy and support only.

I thought this would kind of not jive, and then when we talked about collective advocacy...and how we individualized advocacy, well that's, you know, very very different...something that we're, we're not mandated to do [referring to collective advocacy]. so we'd really have to look at how we would proceed in a partnership like that. ON-LINE DOCUMENT: Ph 2 - Int QO*971.

During the second workshop it became evident that when supporting the development of a partnership, it is important to consider that people may have different views of the partnership relationship and therefore have different opinions about what is needed to support the development of the relationship. As a participant observer, I was able to see distinct differences in perceptions that existed among participants and in particular between the two co-facilitators, a representative from an Independent Living Centre and a representative from a Women's Centre. The main dilemma was that during the workshop, some women wanted to work on getting to know one another while others wanted to develop action plans for collaborative projects (Community Report 1). Although there was not a clear split of opinion between the two groups, the disability representatives tended to
want to have more time for the partners to get to know one another and
develop personal connections through a process of examining stereotypes,
commonalities and differences.

One participant who was a disability representative expressed her
perception of the struggle between the two co-facilitators as follows:

But they're both [the two different approaches: action planning and getting to know you
activities] bona fide, and it's really good to hear...We can have the same issues but it's really
interesting to see where each is coming from...and how they're perceived...but that is the
kind of thing that...all comes out when you get a chance to sit down and talk with one
another. ON-LINE DOCUMENT: Ph 2 Report*129.

A participant involved in the activities of Women's Centres, described,
with reference to the workshop experience, conflicts stemming from a lack of
common vision of the evolving partnership relationship:

I really think that some of the tension that came out in that workshop...the workshop was
designed based on a certain stage of the Independent Living movement...the stage for the
differently abled identity to be known in its fullness...But...the women from women's
centres, from going through a similar process as feminists, were completely ready to move on
to the next stage of strategic planning. ON-LINE DOCUMENT: Ph 2 - Int PO*259-265.

Making Power Explicit

Several participants expressed their personal theories about the role
of power in partnerships. Many participants spoke in their interviews about
inequities within partnerships. One participant stated, “I don't believe partnership
is equality. I think in any relationship...certain people have the power." ON-LINE DOCUMENT: Ph 3 Pre
GERALD* 93.
When I asked the same participant about how it might be possible to build more equality in partnerships, he speculated:

Well I think the first step would be like... and some people can do it and some people can't... You've got to be really out front and open about it...you've got to really disagree. You know, you've got to say...we've got to use the words for what they are and say, like 'well, I think you're going to have a lot of control there. I don't feel like I have much control.' So we can talk about sharing the control...And understand that we all have an agenda. ON-LINE DOCUMENT: Ph 3 Pre GERALD*290-301.

Another participant explored the role of context analysis in his approach to partnership, and his consideration of historical, economic and political variables in determining the amount of control that he requests within a partnership. He outlined the approach he has developed for working with large partners:

To distribute power and to deal with issues of power in an equitable way, that means as equal as possible. In some cases, for obvious reasons, when it's coming to government, [or] when it's coming to what I call those big organizations, I would like to be in control -- because [for] people with disabilities in general, and this is from my knowledge of being oppressed for so long...being in control would be much better. ON-LINE DOCUMENT: Ph 3 Pre FABRICIO*37.

He gave an example of a particular experience that illustrated that the power in partnerships can shift over time among the partners.

The association [where this participant worked] was having a big fight with the union...actually we were having a labor relations war, fighting quite hard and then the common threat that the college might be closed [arose], then we [struck] a deal and we
fought together and we won. And after that, we returned to the bargaining table to fight again, to fight each other again. ON-LINE DOCUMENT: Ph3 Post FABRICIO*191.

Working to prevent the replication of dominant relations of power was another theme that arose in the study. Several participants involved in the third workshop were working to understand the nature and source of power and how it influenced the participation of people with disabilities in community partnerships. In the quotation below, one participant challenged commonly held beliefs about power in partnerships.

Well I think, basically people believe that you're supposed to have a balance of power [in partnerships]. All members are considered equal, however, it's usually weighted in some way by funding, which kind of throws everything out of balance. Because nine times out of ten, the government department or the corporate sponsor, or whatever, that is providing funding for the partnership tends to feel like they have a little more muscle because of their funds. ON-LINE DOCUMENT: Ph 3 Pre JOANNE*98-100.

One participant described the need to reach out to other people that the disability movement may have been excluding, thus illustrating changes that she could make to alter traditional distributions of power among people who have disabilities.

I think all of us need to recognize our strength...to have our own identities and needs clearly stated, but then to reach out and recognize there are other identities and needs that also have to be recognized and integrated with this...and that takes a lot of maturity in general, not just in our movement. ON-LINE DOCUMENT: Ph 2 - Int UO*637-641.
Positive outcomes such as developing new service delivery models and facilitating community development were discussed. However, many of the positive outcomes that were described in this chapter, such as respect and trust, relate directly or indirectly to interpersonal relationships. These variables, that influence interactions within the context of groups of various sizes, appear to represent a struggle to understand one another and live and work together. In addition, several characteristics of group processes that might be used to foster the development of an improved relationship, such as creating a relaxed atmosphere and taking collective responsibility for providing access accommodations, were also explored. These interpersonal and environmental variables were considered by several participants to be influential in bringing about a transformation in the way people behaved. There was a need, as described by several participants, to incorporate an intellectual analysis of social, historical, political and economic variables that affect the way partners perceive an issue and the possible actions that might be taken to address it. By making power explicit, it was believed that people can challenge others and themselves to look for new ways to more equitably redistribute power.
CHAPTER 7
DISCUSSION AND CONCLUSIONS

Personal Reflections about Methodology

There were several ways in which I wanted to conduct this study so that it would be consistent with Independent Living Philosophy (DeJong, 1979) and Participatory Action Research principles (Hall, 1975). Of primary interest was my desire to value the lived personal and community experience of people with disabilities. I also wanted to alter the social relations implicit in research production so as to make the research of direct relevance and benefit to people with disabilities as discussed by Oliver (1992).

Employing Critical Pedagogy

A critical pedagogical approach emphasizes the value of the interaction among people in the process of creating new understanding and potential solutions (Freire, 1993; Lather, 1986b; Simon, Dippo, & Schenke, 1991). I explored critical pedagogy through readings and allowed the work of others to influence my research process in the third phase. I came to believe that critical pedagogy would not only foster a process for participants in the third workshop to examine key issues from the previously collected data but would also facilitate a reflective self-questioning approach for me while in my new role of co-facilitator. In
preparing for the third workshop, I asked myself questions I came across in the literature, such as, "How does a teacher practice critical pedagogy and not deliver an ideology?" ON-LINE DOCUMENT: Journal#4 p.159. This quotation indicates the efforts that I made to avoid assuming the role of didactic teacher.

One of my specific goals was to challenge people's thinking, practice, and interpretations of experience so that they could become more aware of the potential impacts of their behaviors within community partnerships. ON-LINE DOCUMENT: Journal#4 p.159. Rather than presenting the facts about community partnerships as I interpreted them in the third workshop, I wanted to engage people in examining the issues that arose during the first two phases so that they could come to their own collective and individual conclusions. The goal was to assist in developing richer understandings of some of the major themes and the specific implications for action in each participant's particular context. I also wanted to provide an opportunity for people to question their commonly held beliefs about partnerships and the many roles that people were expected to play. One participant reflected on the third workshop in the following way:

I particularly found the whole aspect, we looked at power and that was one thing I was very interested in and I liked the way it was done, what portions of power belong where and what does it feed into and where does it come from and feed into and how does that component, when the power is balanced, how does that end up strengthening the partnership, how does that help the partnership grow. ON-LINE DOCUMENT: Ph3 Post ANNA*25.
Making Research Useful

My efforts to go beyond a descriptive investigation to one that incorporated action was in part supported by my reading in the area of critical participatory ethnography. After reading the work of Thomas (1993), I entered into my journal the following comment about one of the goals that I wanted to achieve in this research study: "not perpetuate [social relations] with just a description - but work to CHANGE!" ON-LINE DOCUMENT: Journal#4 p.141. Philosophers have only interpreted the world in various ways; the point however, is to change it!

My journal entries reflected my struggle to understand how I might make the research useful. I wrote, for example, "I want to do something useful. [But] How do I determine this?" ON-LINE DOCUMENT: Journal#1 p.42. I also explored the implications of integrating the practical elements into the study when I wrote, "The nature of research becomes blurred between research, intervention, the practical, and theoretical." ON-LINE DOCUMENT: Journal#1 p.42. This quotation indicates the balancing act of conducting quality research while also recognizing the needs, interests and desires of community members.

In my position of graduate student, my main role was required to be that of a researcher. My partner organization led the community development activities and created the context for data collection. My desire to do something meaningful and contextually sensitive was reflected in the manner in which this study was connected to the community. By interweaving the research study with existing community activities planned by a disability organization in phases one and two, I was able to assist in meeting this organization's objectives as well as my individual research goals. I attempted to make the research experience nonexploitive by using
the Partnership Agreement Framework to develop a written understanding for each phase of the study. I also made an effort to limit the use of financial and human resources from the partner organization. ON-LINE DOCUMENT: Journal#1 p.244.

The learner contracts developed for the third workshop kept everyone focused on the ways that people wanted to benefit from their involvement. In my opinion, participants also benefited from having an opportunity to intensely examine the issue of partnerships. Individual participants expressed various ways that their thinking had evolved as a result of participating in the third workshop. One woman, for example, stated: "Now I'm looking at a partnership as something I can negotiate." ON-LINE DOCUMENT: Ph3 Post JOANNE*113-120. This quotation illustrates a sense of empowerment that this woman could bring to the process of reestablishing power within collaborative community partnerships.

**Multiple Positions and Roles: Consumer Researcher**

My social position is that of a white middle-class female who is occupied as a full-time graduate student and part-time professional researcher. While involved in this study, I also identified myself as a person with a disability or as a person who had direct experience living with a disability; my health status improved during this study to a point where I questioned whether my body met the physical functioning criteria for using this label.

My interpretations of my own life experiences may have influenced the emphasis that I placed on critical analysis. When I came across the concepts of hegemony and critical pedagogy (Giroux, 1992; Simon, Dippo, & Schenke, 1991) in the literature, they immediately resonated with my
personal experience within the disability community. Over time, within this study, I became increasingly aware of the role of power in the dilemmas that many people with disabilities appeared to face. I wanted to understand how people could play a role in counteracting the replication of power relations rather than replicating or reinforcing them. I also wanted to involve people with disabilities who were leaders in this approach so that they might bring about change in the context of their own lives and work.

As a researcher, I wanted to explore how my multiple roles and positions affected the participants' experience in this study. My location as someone with ties to the disability community allowed participants, at times, to assume a common level of basic understanding within our interviews. ON-LINE DOCUMENT: Ph 2 - Int D*37. I felt that this allowed us to move quickly into deeper discussions and analysis of issues. In an interview I asked a participant how she felt about my consumer-researcher position. She responded:

Because of your own background and different experiences you've had...that you've shared with us...I really think that if you hadn't shared this, I would have came away feeling a lot different about it than I did...When I feel that people don't have the experience and don't really know the issues, then I...just go into the advocate mode and feel that I have to be educating them all along on something rather than getting to the issue at hand. ON-LINE DOCUMENT: Ph3 Post CLAUDIA*173-222.

Although there were benefits related to my dual position, there were also ways that my position negatively affected the study's goals. I believe that my position as a person with a disability involved in disability groups interfered with my ability to absorb certain types of information. I realized
that it was harder for me to see things that affected me personally. In a journal entry I stated, "It was very close to home for me and this may have unconsciously led me to be resistant" (ON-LINE DOCUMENT: Journal#2 pp.165-166). I recognized that I could not fully accept what one of the interviewees was telling me, namely that people affiliated themselves with community groups to meet personal needs, not to bring about social change, although both may occur (ON-LINE DOCUMENT: Ph 2 - Int PO*15-22). Once I recognized this point, it directly influenced my conceptualization of the issues and the analysis that I brought to the thesis.

My approach in this study was to attempt to use journaling to facilitate constant reflection, document decision making and make transparent my evolving understanding of collaborative community partnerships. As I reflected on the experience of conducting this study, I can see that my human fragility, sensitivity and fallibility influenced my attempts: a) to implement a methodology in a complex environment; b) to define and redefine myself during the period of this study; and c) to recognize that themes from the study have affected me before, during and after their discovery in the data.

**Partnership as a Process**

Based on the analysis of the data collected in this study, an understanding of the dynamic processes of partnership can be developed (see Figure 1). Collaborative community partnerships are influenced by their broader social, economic, political and historical contexts. However, the core of a partnership is comprised of the belief systems held by the partners involved. Three central belief systems were identified: Medical Model,
Figure 1. Process of community collaborative partnerships.
Charity Model and Independent Living Model. These represented distinct ways of viewing (or socially constructing) disability. These perspectives influence the type and level of barriers experienced by people with disabilities. They also influence people's opinions about the appropriate approaches to use for addressing disability-related issues. Those who hold a particular belief system, however, cannot be assumed to belong to a certain group characterized by disability status or professional training, that is, some people with disabilities may operate within a Medical Model and some service professionals may operate within an Independent Living Model.

It is from these different mental models that conflicts of values and beliefs originate. A partnership process that emphasizes and utilizes a medical or charity model of disability may produce some form of legitimate and valuable outcome such as a medical intervention program. However, with respect to attaining a goal of partnership in which people's values and beliefs are shared, supported and integrated, the participation of people with disabilities can be considered to be token. Alternatively, people with disabilities may choose to ground a project in the Independent Living Model of disability, and may produce a legitimate and valuable form of action, such as a peer support program. This form of action would not, however, be considered a partnership.

In order for a partnership to be successful there appears, based on this study, to be three basic preconditions: a) partners must have a desire to work in partnership, b) historical and present power imbalances must be recognized, and c) all partners must accept responsibility for working to redistribute the balance of power more equitably within the partnership and among the members of the group that they are representing. Within this
study critical pedagogy was used as a guide in acknowledging power issues and the Partnership Agreement Framework was explored as a method of making explicit arrangements for addressing power imbalances. When these conditions are met, a community partnership may lead to personal transformation, collective action and broader social change.

Conflicts in values and beliefs can lead to several forms of action. Members of the partnership may choose to recognize the impact that different mental models have on power sharing and agree to work together to recognize and address such issues. On the other hand, the most prevalent conceptual model of disability within one partner group may dominate the interaction, such as a medical model of disability among health care professionals. This might lead another group, such as people with disabilities to leave the partnership as a result of not having their perceptions and specific concerns validated and acknowledged.

People with disabilities who leave a partnership may in turn choose to work on a disability-related issue in the future in a manner that emphasizes the beliefs and values of the Independent Living Model and consumer control. These people may choose to either work independent of other partners or enter into a partnership when they are assured that some level of consumer control can be incorporated into the working relationship. Consumer control, in the form of arrangements to ensure that the voices of people with disabilities are heard among the other members of the partnership, thus play an important role in reconfiguring the dominant relations of power. I believed that working with strong linkages to people with disabilities in the community would increase my ability to capture and verify their perspectives of partnership. This was seen as an important foci
because of the limited literature in the area. I also felt that my personal experience at the community level might place me in a unique and valuable position to explore such perspectives.

**The Role of Beliefs and Values in Partnerships**

**Social Construction of Disability**

One's experience of disability is to a large extent influenced by the way people in society socially construct the concept. As discussed in this thesis, people who are viewed within a medical or charity model of disability often face barriers that are only minimally related to any actual impairment. Therefore the social construction of disability frequently involves disempowerment for people with disabilities. Services which are designed and implemented by people who hold limiting and patronizing perspectives of disability can be disempowering and disrespectful of people's capacities. Hence, it is imperative to challenge assumptions about disability that underlie such services (Wendell, 1996).

Partnerships that include people with disabilities provide a potential opportunity for them to contribute valuable expertise to the development of a project, object or service. Expertise will likely be present in direct concrete suggestions, as well as in more abstract indirect forms, for example, personal stories that serve as metaphors. People with disabilities can also provide a set of beliefs and assumptions about disability throughout the developmental stages that make the "product" more suited to utilize human potential and perpetuate positive images of disability.

Social constructions of disability (Wendell, 1996) and common-sense notions about what is appropriate (Ng, 1993) create handicaps. That is, a
A person with a disability may face great barriers in one environment but may not experience limitations in another. A person with a disability may be restricted in his or her ability to participate in a group because the members of that group employ limiting constructions of disability and rigidly impose notions of what is appropriate in terms of the form of contribution. This same individual would be able to contribute fully in an environment in which people think about disability in terms of assets and capacities, and who are interested in challenging commonly held notions about what appropriate behavior is. In accordance with the ideas of disability theorists, people need to recognize the responsibilities they have to reduce the barriers that are created within the mind (Wendell, 1996).

The Independent Living Model of disability, which recognizes the capacities of people with disabilities to make choices that affect their own lives, was succinctly expressed by one participant who had a disability affecting vision and learning, when she stated: "I can do everyday things. People think I can't." This quotation highlights the contradiction that exists between what is real and what is perceived.

Participants involved in this study illustrated on numerous occasions that their experience of inclusion in partnerships was influenced by the ways they were viewed by others. In keeping with a medical model, some participants felt that nondisabled people focused on their disability and developed low expectations regarding contributions. Others described how they were viewed as if they were children, incapable of making decisions in their own best interests. When either of these approaches to thinking about disability was employed within partnerships, participants were left disregarded, unappreciated and effectively blocked from participating fully.
Participants described how the use of a charity model interfered with the process of establishing new, more equitable roles for the partners involved. As one participant had stated, the “gratuitous goodwill” approach leaves the people who see themselves as benevolent providers reluctant to give up their role. She said, “presumably they invited you or your organization to participate in the partnership because they want the perspective of someone who has a disability right? And then you’re cut out because they can’t get past this thing – that image [of people with disabilities] and self image [provider of charity].” In order to adopt the use of a more capacity-oriented view of disability, people in partnerships need to demonstrate flexibility in the way they view themselves and others.

Participants with disabilities, however, described harsh reactions when they stepped out of their socially expected roles. As one participant had articulated, “As long as you’re meek and mild and do what you’re told and keep your place, they’re happy with you. But the moment that you become independent and have your own opinion and start speaking up, they don’t like you so much. All of a sudden you are a challenge to them.” This quotation illustrates a number of points. First, the satisfaction of the partner with the docile behavior may originate from the comfort of both parties playing expected roles. Second, when persons with a disability display outgoing behaviors, they are rejected. Third, people with disabilities often recognize that they are challenging nondisabled people, challenging the latter’s thinking, behavior and position of power.

People with disabilities negotiate, on a daily basis, the constructions of disability that others impose. Several of the participants clearly articulated, from their perspective, how they were viewed by others and challenged the assumptions used. For example, one participant had said, “upper-middle-class thinking...you have to go to...finish high school and go to university and get your profession and then, you know, the whole bit...She can't perceive [who I really am]...[in her mind] I'm T
sort of uneducated mental health person dealing with a mental illness...hard luck in life...that [mental illness] can only happen to someone like myself...Where it can happen to a professional just as easily. But...I think there’s this concept that nothing like that could happen to someone’s who’s educated.” This participant summarized the perspectives that make up what she refers to as “middle-class thinking,” and she pointed out how she is rejected as a result of not meeting the criteria for an appropriate level of education and professional development. She confronted one of the assumptions that she perceives service providers to make about who can acquire a disability. I suspect that the reason why this participant raised this point at this time was because she had, she presumed, experienced personal distancing from professionals because at some level they feared the possibility of acquiring such a stigmatizing disability.

Many social science researchers have discussed the process of othering (see for example, Fine, 1994), that is, reacting to the rejected part of the self that is projected onto another person. Able-bodied people may have to confront their fears about their own body’s vulnerability to illness, disability and death before they can view people with disabilities more accurately (Wendell, 1996).

It is critical to examine some of the possible reasons for the anger that is elicited when people with disabilities become vocal and attempt to play a role that differs from expectation. In such a situation persons with a disability challenge both the able-bodied person’s expectations of a passive recipient, but perhaps more importantly, also challenge the latter’s position of charitable caregiver. Those who are attached to a charity model of disability may interpret the disabled person’s behavior as ungrateful in an attempt to maintain, in their own eyes, their status of a charitable caregiver.
The particular construction of disability employed affects a person's ideas and actions. Therefore, altering the construction from a medical or charity model to an Independent Living Model may result in the elimination of many different forms of handicaps experienced by people with disabilities that are created by people in the environment in general, and community partnerships in particular. People with disabilities are ready to participate more fully in partnerships. Some disability representatives are interested in playing a leadership role to guide other partner groups in understanding the capacities, needs and interests of people with disabilities. In order for these types of changes to occur, however, medical and charity constructions of disability will have to be challenged, deconstructed and recreated to more closely fit a model such as Independent Living in which the capacities of people with disabilities are recognized.

**The Work Process within Partnerships**

People with disabilities are frequently not seen as able to fit into the generic requirements for productive work. Within our society people are expected to produce objective outcomes that can be quantified or described through text. Work is also expected to be produced over a short period of time with a limited amount of financial resources. Gramsci (see Sassoon, 1982) would categorize these as some of the common-sense notions that represent the taken-for-granted nature of ideological thinking (Ng, 1993). Such incoherent or arbitrary beliefs that are generally held by mass society underlie what people perceive as ordinary and appropriate ways of doing things. Belief systems that impose normality are problematic for people
with disabilities who frequently achieve the same goal but through the use of alternative means.

For people with disabilities, arbitrary rules can create handicaps; for example, certain expectations around the pace of work can create barriers for some people who could otherwise perform the required tasks (Wendell, 1996). Providing access accommodation for people with disabilities, something essential to a basic level of participation, is often viewed by members of society as time consuming and expensive; some question its feasibility.

Throughout this study, there were several examples of how common-sense notions functioned to limit the participation of people with disabilities. I recall the comments of a service administrator who had stated, "We have to be fiscally responsible. We have to be inclusive, but we've also got to be realistic." These likely underlie the attempt on the part of the professional service providers in this partnership to form a core group to take on the primary responsibilities of the group.

In addition to identifying the reluctance to expend funds on providing basic access accommodations, there were several ways that arbitrary time constraints more subtly limited the opportunities for people with disabilities to participate. This was exemplified by the comments of one woman who stated that a meeting that ran too long and without breaks or meals left her unable to concentrate. She also described the impatience of others to listen to her contributions when time was limited. Notions about time, therefore, acted to systematically reduce the potential quality of input if it did not limit it altogether.
As described in the discussions about the second workshop, several women with disabilities including the representative from the research partner organization believed that it was crucial for the partners to spend time getting to know one another. I suspect that this strong conviction was grounded in past experiences of being misunderstood by people who thought that focusing on a common goal would be sufficient grounds for establishing a working relationship. In this case, some participants felt it was important to develop a relationship of trust and respect as a significant outcome whereas others felt that developing an action plan for a collaborative project was a better use of time. This conflict regarding appropriate outcome depicts people with disabilities in a position of challenging the common-sense notions held by members of society.

Common-sense notions that typically go unnoticed are incorporated into our work practices and effectively keep certain people in marginalized positions (Bourdieu & Passeron, 1977). Therefore, when such conceptions are applied to the work process within partnerships, the partnership is more likely to mimic dominant relations of power that exist in society and limit the meaningful participation of many people with disabilities.

As illustrated in this study, ideas about time, outcomes and use of resources all act to limit the contributions of people with disabilities in working relationships such as community partnerships. If partners are serious about including people with disabilities, they must, on ethical grounds, provide basic access accommodations (Krogh, 1996). In addition to this, however, partners need to stop and think about how certain common-sense ideas can have a significant impact on people with
disabilities, their contributions and the quality of the work produced by the partnership group.

**Role of Emotion and Creativity in Articulating Lived Experience**

Lived experience has been described extensively as a valid, although not commonly recognized, source of knowledge (Freire, 1993; Ng & Ramirez, 1981; Smith, 1991; Weiler, 1994). One key component of the experience of living is emotion. When communicating about lived experience, emotion can be an indicator of significant feelings, events and circumstances. Other forms of expression such as drawing, drama and story telling can also be used to represent what people know.

This articulation of knowledge is important as a contribution to the collective work of a partnership. It also contributes to the self-understanding and development of critical consciousness that Freire (1993) identifies as a crucial phase in the process of altering relations of power. Researchers have discussed the value of using stories and other forms of creative expression to capture meaning (Heron, 1996; Van Manen, 1994). Story telling can represent a valuable process in which a participant selects the most important themes and events in a concise manner, thus eliminating some of the tasks that are typically performed by the researcher (Seidman, 1991).

When people with disabilities incorporate emotion into their communication, they are frequently discounted altogether. When forms of conveying knowledge such as art and drama do not fit within common-sense ideas about what is legitimate, the content ideas are also typically discounted. Participants in the third workshop described in detail how they
felt caught because they wanted to express their emotions in order to represent issues and ideas holistically; however, as a result of the delegitimizing reactions of others, several experienced a need to control and limit emotional expression: "They use it [the expression of emotion], it's like she's a woman or she's too emotional or she's disabled, or you can find all kinds of reasons [to diminish the validity of the contribution], and that's unfortunate because although factual stuff is important the emotional part is also important...we almost have to shut that emotional side down -- so you're not really coming at it from a holistic perspective." This example illustrates the many rationales that disabled persons may encounter that delegitimize their contributions. It is unfortunate that people with disabilities have found that they have to convert the holistic presentation of their ideas to conform to acceptable standards rather than other people developing a greater flexibility about what is appropriate.

Creative learning methods that incorporated drama and art were described by participants as effective thinking tools that fostered the development of a more comprehensive understanding of the issue being explored. One participant, for example, stated: "those kinds of exercises really make you stretch your thinking...when we go into something as cumbersome and serious as...policy...we don't stop and stretch our minds, to put our heads around all of the parameters." These conclusions about the value of these activities as information-gathering and analysis tools run counter to commonly held beliefs about the appropriate forms of expression one should use to express expertise.

These types of activities were found to draw out the expertise of some of the participants with disabilities in a manner that was more suited to their learning styles as well as communication and cognitive abilities. When one participant was observed to increase her level of participation through role play, another participant had stated, "After that [role play], wow, "I'm
here!”, she was saying, I have something to report today for your benefit, people.” Hence by providing alternative forms of activities that elicit information and support analysis of issues, one can increase accessibility and participation for some people who have disabilities.

There was some recognition on the part of people with disabilities that, although these activities may be effective, they do not fit into the dominant ideology of an appropriate information-sharing process. As a result there would be a reluctance on the part of some partners to engage in them. As one participant articulated: “But it also challenges people because we’re rarely invited to express ourselves in that way...It’s not objective, it’s not formal, it’s not standardized...you know, it doesn’t meet the criteria...its silly really, the untapped potential in people...it just blows me away.” Later she elaborated: “We don’t have permission to be creative, we don’t have permission to use every part of ourselves in the jobs that we do. We are supposed to focus our attention cognitively and that’s it.” This exemplifies both the influence of an established set of expectations and the significant drain of potential that results from employing these ideas in our practices. People who are especially disadvantaged by these ideas include people who have certain forms of disability, such as a speech-impairment or learning-related (developmental) disability, as well as people who have not been trained in the use of institutionalized methods of formal communication, people who have different learning styles and individuals who have limited literacy skills.

People with disabilities have valuable expertise based on their lived experience with disability. This expertise can be effectively communicated through drama, art and story telling, forms that arguably may more closely represent the realities of some people with disabilities than words since they are easily shaped by society’s beliefs, slogans, phrases, and doctrines (see Freire, 1993; Ng & Ramirez, 1981). The contribution of such expertise,
however is frequently ignored, rejected, and discounted, according to the accounts presented. Rather than feeling free to communicate about personal experiences and feelings, many people with disabilities find themselves expending energy monitoring the reactions of able-bodied people and limiting their level of emotional expression accordingly, in part to avoid being pitied or delegitimized.

Common-sense ideas that are often arbitrary and exclusionary are also at times counterproductive (Bourdieu & Passeron, 1977); on the whole, society loses. The participants in this study found that expression of emotion and the use of creative learning methods were effective strategies for expressing life-based knowledge and developing an analysis of relevant issues. Yet there is recognition that these forms of expression, ideally suited for the contribution of life-based expertise, would not be generally used or considered acceptable. The act of applying common-sense ideas about appropriate forms of communication, learning and information sharing therefore can systematically act to prevent one of the most valuable contributions that people with disabilities can make to partnerships.

These ideas have serious implications for the structure and processes used within community partnerships. If able-bodied people are serious about their commitment to inclusion, they will seek to become attuned to the ways that people with disabilities may want to express their expertise. Although some people view the use of drama and art as simplistic, in my experience this approach actually involves many analytic, cognitive and integrated emotional processes. All people involved in using these methods need to be willing to expend the effort to draw meaning from the symbols involved.
Representing Disability

*Diversity of Perspective among People with Disabilities*

People with disabilities, like women, are a heterogeneous group. Issues related to heterogeneity within an identified group have been described by hooks (1984), Ng and Ramirez, (1981) and Lorde (1984) who use the women's movement to illustrate the mistakes that have been made when white middle-class, heterosexual women assumed a position of representing women of color, women with different sexual orientations and women of different ethnocultural groups. The false assumption of homogeneity creates a norm to which all members are pressed to adhere (Lorde, 1984).

There are many forms of difference among people who have disabilities including the form of disability, extent or severity, level of visibility and time and process of acquisition. Further, disability status itself represents only one of the many ways that people identify themselves. They may also be recognized, for example, in terms of their gender, race, immigrant status, socioeconomic status, profession or unpaid work activities.

People who may share in some of the above dimensions, e.g., disabled women, may nonetheless have very different life experiences, expertise and issues of concern. (This is not to deny that common interests do exist. Among these is the need to confront the social construction of disability within charity and medical models and to reduce barriers that create handicaps.) Issues of diversity raise challenges for people acting as representatives who are attempting to express the perspectives, ideas and issues of people with disabilities.
Some of the difficulties that have resulted from the view that people with disabilities constitute a homogeneous group include the belief that a single person can represent the views of people with disabilities solely because they themselves live with a disability. Other difficulties arise from the assumption that without a network, ad hoc committee or formal disability organization affiliation, an individual can democratically represent a range of views. A third challenge arises when some people with disabilities believe that one organization with a particular set of characteristics is in a better position to represent people with disabilities than another.

People with disabilities within this study expressed several concerns related to the assumed homogeneity among people with disabilities. Problems occur, for example, when all people with disabilities are assumed to hold a single perspective. This is the equivalent of saying all women or all people who wear glasses should share the same opinions. An extension of this assumption is that any single person who lives with a disability can represent all people with disabilities.

A common theme was the importance of having a process through which representatives are selected by and accountable to people with disabilities. As one participant stated, “She has a great deal of knowledge in that area [topic of the partnership] but now they [people with disabilities] really resent her, speaking for them because they didn’t ask her [to] nor will they ever know what she said [as their representative].” As this quotation illustrates, the act of formal representation, such as that found in community partnership, requires consideration of many different perspectives within the group of people who live with a disability.

With respect to competition among disability organizations, one participant made the following statement in describing turf wars among
disability organizations: "I find turfing a huge problem inside the disabled community." Later she elaborated, "We have to fix those inherent problems or we're never going to be forming wonderful partnerships...the first partnership we have to learn how to form is within our own disabled community." There are several concerns that turf wars raise; the most immediate problem with them is that they waste limited resources.

A second major concern was articulated during the third workshop when a metaphor of a better future was created by the group of participants. Within this scenario, different people with disabilities came together to collaborate in making bread to feed themselves so that they would not have to receive limited amounts of bread from a powerful party in a manner that helped cause subordinated persons to become aggressive toward one another. Turf wars, it was implied, may serve the interests of dominant powers. People, distracted by confronting one another within their group, are unable to challenge dominant structures, a process that has been discussed in relation to black men and women by Lorde (1984).

Diversity is also found in opinions and philosophies. A few participants discussed the need to be cautious about using dogmatic approaches requiring all members to conform to a single method that is presumed to be better than all others. As one person stated, "trying to get everyone in line...if we think that that is our goal and that our power comes from when we can all act as a unified voice, then what we are doing is imposing the same dead nonthinking, noncreative interaction between ourselves...this [is what] dominant culture is made of." Disabled persons, this participant suggested, may in fact be replicating the same forms of thinking and behaving among people with disabilities that they are trying to change in the broader society. Thus all people, regardless of disability status, would benefit from challenging themselves and one another about imposing
expectations about the way it should be, and remain open to creatively and critically approaching the formation of new ways of relating to other people.

As illustrated, the process of representation is complex. Within a partnership, issues related to representation and diversity will require the attention of all partner groups. A disturbingly common practice that people must become more aware of and challenge occurs when someone selects the first person who comes to mind who has a disability regardless of how that person sees him or herself (e.g., as a computer programmer rather than as an advocate for people with disabilities), and how he or she is connected to a broader community of people with disabilities. Issues of diversity among people with disabilities will have an impact on the process used to select a representative as well as the mechanisms for accountability and input. The important role that disability organizations can play in supporting a disability representative politically and personally was made evident in this study.

Having presented concerns about representation, I feel I must also comment about the dominant group’s use of unrepresentativeness to actively shut down or reject vocal disability representatives. Beresford and Campbell (1994) describe a situation where service providers and their agencies express concerns about getting unreliable, inaccurate or biased information from disability representatives, while people with disabilities who are involved identify the problems of being devalued, undermined, and ultimately excluded by being challenged on the grounds of not being representative enough. Beresford and Campbell caution against this line of argument when the process of being involved in a community project can alter a person. In some situations, the disability representative may develop
greater skills, awareness and confidence. Thus the same characteristics that can act to add strength to the voice of people with disabilities in challenging dominant relations can be used as an excuse for exclusion by members of a more powerful group. It is difficult if not impossible to represent all people. Representativeness, a responsibility for all partners, cannot be allowed to be used as an excuse for exclusion.

Disability organizations could probably benefit from developing stronger linkages that would support a collective and critical perspective. They need to redirect the energy used on turf wars within the community to more strategic targets outside of the disability organization sector; a broader and critical perspective may be prudent. Turf wars reduce the energy that could otherwise go into a partnership; in particular, people with disabilities may become distracted from seeing and addressing issues that involve altering the relations of power.

**The Oppressed as Oppressor**

Bourgeois white women, writes hooks (1984), worked to obtain power by accepting the terms set out by the existing social structure. For many, this approach was based on the belief that women as a group were different from men and would exercise power differently. She points out that although women have less power than men, they often do not conceptualize power differently. People with disabilities can learn from the struggles within the women's movement as well as the struggles of illiterate peasants with whom Paulo Freire worked.

Paulo Freire (1993) believed that efforts to bring about change should not merely be focused upon the oppressive situation between one group and
another, but also upon the interactions among members of the oppressed group. People who are oppressed internalize oppressive ways of relating and impose suboppression over others within the same group; as a result, people of lesser power must be encouraged to challenge the oppressor within. It is through critical consciousness, he proposed, that the oppressed can become more aware of these patterns and create new ways of interacting among themselves and with others. The work of Freire may provide several lessons for people with disabilities. People with disabilities can be reassured that suboppression is a common issue connected to the way people learn to think about power and not related to the particular inadequacies of any single group of oppressed people. Following this reassurance, people with disabilities need to accept the responsibility for addressing suboppression.

The two forms of oppression that were most frequently described by the participants in this study were ablism and sexism. Ablism within the disability movement is similar to the discrimination that exists among other members of marginalized groups. For example, people who have lighter black skin are frequently treated preferentially over people who have very dark black skin within this subpopulation. One might believe that since a person has experienced oppression, he or she would avoid dominance when relating to others; discrimination hurts whether it be in the form of racism or ablism.

Acknowledging suboppression and the conservatism that supports it is difficult, even when the process is understood intellectually. This was illustrated by the comments of one participant who referred to the oppressive and inflexible character of the disability movement: “When I first started working in the self-help aspect of things I had an expectation that the disabled community, for example, was not going to have elements of conservatism in it.” Later she elaborated, “I have an
intellectual understanding of why that is, but my heart is always taken by surprise." Confronting suboppression can be difficult emotionally, and as a result, dominant relations continue.

Another participant described the difficulty that she had with ablism as it was expressed by people with some forms of disabilities toward people who had different types of disabilities. A particular episode of discrimination she recounted, as described in Chapter 5, took place during the Annual General Meeting of a cross-disability organization, an organization that had a mandate to serve people with all forms of disability. The participant explained that a woman, who could not talk, "kind of made a lasting kind of yelling noise," to express her excitement about her favorite topic; another person who had a mental health disability spoke openly about issues that concerned him. Some people with disabilities felt that such contributions were not acceptable and wanted these individuals to be excluded from future meetings. This scenario illustrates how people with disabilities may have internalized mainstream ways of relating and the accompanying belief system. The form and content of these contributions did not meet the commonly held criteria for acceptability. People with certain forms of disability are viewed as more or less capable, efficient and therefore legitimate in the role of spokespersons. The descriptive words "effective" and "efficient" conform to the dominant society's view about time, communication behaviour and form of contribution as well as ability. It is crucial for people with disabilities to challenge these ideas for themselves, as well as members of other oppressed groups and all people in society generally.
Discrimination in the form of sexism was also described by participants. One participant described a common situation within the disability movement in the following way: “There's formal power brokers and informal power brokers [within the disability movement] and they're mostly all men, they're all men.” This quotation exemplifies the internalization of sexist practices among people with disabilities. It also illustrates the use of an arbitrary marker, gender, that results in the subordination of certain groups of people (Bourdieu & Passeron, 1977).

Women who have severe and salient disabilities experience a great deal of disadvantage in society. Several authors have introduced the concept of multiplicative effect of double or triple disadvantage. Ng and Ramirez (1981), for example, described the barriers faced by women who are also immigrants in Canada. Similarly, women with disabilities experience greater discrimination than men as a result of sexism. In addition, the more a disability differs from expected norms in relation to body shape and communication process for example, the greater the social, economic and political barriers faced. Therefore, we can conceptualize three layers of discrimination for a woman who, as a result of disability, uses a speech-output device rather than speech to communicate. Discrimination based on gender, race and disability type likely account for the historically predominant place of people who are white, male, spinal-cord injured in leadership positions within the disability movement in Canada (Boyce, in press).

These issues indicate that it is important for people with disabilities to examine power not only between sectors but within marginalized groups. The examples provided also highlight the tendency for people with
disabilities to adopt commonly held beliefs and structures that result in the perpetuation of oppression through sexism and ablism. It is through both critical consciousness raising and commitment to change that transformation may occur.

Some people with disabilities have begun to articulate and challenge oppressive structures and beliefs that are commonly employed within the disability community. Women and people with severe and salient disabilities can expect, based on history, that their struggles will be intense. All people with disabilities are encouraged to seek the many sites in their daily lives in which change in relations of power is relevant as a step toward creating a more equitable society.

**Power in Partnership**

**Consenting to Existing Power Relations**

People who have less power than others within society have a tendency to conform to the dominant relations of power consciously or unconsciously (Bourdieu & Passeron, 1977; hooks, 1984; Lorde, 1984). This may result, for example, from having been constantly exposed to these social conceptions or from a fear of rejection. As previously discussed, people with disabilities are susceptible, as are members of any marginalized group, to internalizing dominant conceptualizations of power. The fear of rejection or seeking acceptance are particularly relevant for people with disabilities.

Some people with disabilities accept and adopt the image, role or label that has been created for them by others in such a manner as to support the dominant group’s interests. The adoption of an expected disabled role
can take place within an unauthentic partnership at both the individual and organizational level. For disability representatives, this may take the form of behavior that is passive and appreciative. By agreeing to participate in this way, people with disabilities and their affiliated organizations perpetuate the false image of equity that is typically associated with community partnerships. One participant described this situation as follows: "If they're not willing to voice their opinion they tend to throw the committee out of whack further because it looks like it's consumer controlled, but it's not." In the situation described above, people with disabilities have agreed to participate even though they are not comfortable vocalizing their ideas. There are many reasons why this might take place.

Several participants described how some people with disabilities may assume that being asked to participate is a step forward in terms of altering the positions that people with disabilities are often expected to occupy in society. This approach, however, relegates the representative to playing the same passive disabled role but in a new location; thus it is a reconfiguration of the same set of power relationships.

People with disabilities experience many forms of rejection from society. Some people, who participate in CCPs, it was suggested by participants, may be seeking a way to achieve acceptance within society for themselves as individuals, for people with the same form of disability or for their disability organization. The approach employed in these scenarios apparently reflects that described by hooks (1984): Women who accept the dominant relations of power assume that once they obtain power they will be in a position to share power more equitably. She has warned that this process actually reinforces the dominant power structure.
Individual characteristics such as self-esteem and willingness to articulate concern were discussed by participants involved in this study as important criteria to consider when identifying a disability representative to join a community partnership. For example, one participant described her organization's approach in the following manner: "We're very careful that we have enough consumers on it that are relatively vocal, strong, opinionated...that aren't afraid to voice their opinions." Although individual characteristics are important, it is crucial to examine the limited opportunities for such features to be encouraged. Rather than dismissing younger or more reserved people with disabilities from participating in representation activities, I support the suggestion of several participants of the third workshop to increase opportunities for developing critical thinking skills and confidence through mentorship.

Other participants emphasized influence of the sociopolitical context on whether representatives feel comfortable speaking freely. One participant stated: "We could have ten mental health consumers sitting at a table with six people from the medical profession and they're still going to overpower us." The recognition of structures of power is an important part of developing critical awareness. This quotation illustrates that even numbers have a limited impact when people with disabilities are confronted by people whose professional training and position have reinforced power positions. This has implications for the common practice among disability groups of assuming that 51% representation amounts to consumer control.

The connection between personal characteristics and social structures arose in the study. I recall remarks such as the following, about cultural dependency: "People who have been culturally conditioned into dependence and think that...as long as they're docile and pleasant that everything will be fine...There is a cultural dependency with disability, I find that people because they haven't been given decision making, they haven't been given their own power in
their own lives." This quotation appropriately links the passive behavior of some disability representatives to the accumulated exposure to disadvantage and discrimination throughout a lifetime.

Some participants spoke about how they worked to develop structural arrangements of their own to counterbalance those of other partner representatives. An arrangement that I found of particular interest involved a consumer-controlled disability organization in a dominant role. All decisions of the partnership committee had to be accepted by the board of directors of the consumer-directed disability organization. It is essential to establish a process whereby the disability representative can bring information to the board for more open discussion and debate. I can imagine several benefits of such a structure. It allows the disability representative to feel like a meaningful contributor to the partnership committee because her views would need to be considered by other members of the partnership when they presented their proposals. This arrangement would also help ensure that the information formats (e.g., plain language or braille) and analysis processes (e.g., formal business meeting employing Robert's Rules of Order with ideas presented in written reports or facilitated role play to explore issues) were accessible. The direct support of the board could provide an opportunity for a representative to discuss issues in a broader context of people with various experiences of disability. The disability organization's presence and the board's veto power would allow the disability representative to experience a greater level of power than she otherwise would have on a partnership committee.

Power relations within partnerships can be very difficult to detect and decipher, particularly when common-sense conceptions indicate that
everything is operating as would be expected. As discussed in Bourdieu and Passeron (1977), people who are oppressed often find themselves conceding unconsiously or consciously to the roles to which they are relegated. People with disabilities, by thinking uncritically, may in fact be participating in their own oppression. Hence the need for disability representatives to develop critical thinking skills and plan opportunities to share their ideas with other consumers in order to have their ideas validated. Such validation may be helpful when disability representatives face confrontation and rejection from those in privileged positions of power.

Some participants discussed individual characteristics such as self-esteem, however, it is critical to recognize that the problems are rooted in institutional and societal structures and cannot be explained fully through individual variables. It is critical that people with disabilities feel free to reject the role and reality that is imposed upon them. Feminist thinkers such as hooks (1984) and Janeway (1980) describe this process as the power to disbelieve. This form of resistance can lessen the impact of dominant forces. Instead of being grateful for being asked to participate in a community partnership, people with disabilities can, for example, demand certain terms as conditions for participation in partnerships.

**Challenging Power Relations through Consumer Control**

Challenging dominant relations has historically been described as a serious ongoing struggle. This has been described in relation to many groups such as women (Lorde, 1984) and illiterate peasants (Freire, 1993). Articulating one's situation in relation to power is considered an important first step to developing critical awareness and empowerment (Freire, 1993).
Critical pedagogy, a self-reflective process of facilitating learning, has been described as an effective method for fostering what Freire describes as *conscientization*, which is both an awareness of power arrangements and the desire to change them.

Several disabilities theorists and activists have become increasingly cautious about their involvement in collaborative initiatives, such as community partnerships (Beresford & Campbell, 1994; Drake, 1992; Krogh, 1996; Oliver, 1992; Woodill et al., 1992). They propose creating terms or conditions of participation that ensure that issues related to power such as decision making, resource allocation and acknowledgement are addressed when the partnership is first being established.

Consumer control is a concept that represents the desire and efforts of people with disabilities to confront and alter the dominant relations of power. The ways that consumer control may influence partnerships vary from imposing some conditions for participation to deciding not to work in partnership at all. In whatever form people with disabilities determine to be appropriate in a specific setting, it signifies a shift in paradigm.

Several participants in the present study recognized that entering into a partnership represents a risk when the level of involvement is unspecified. This risk, I propose, is grounded in the fact that without explicit alternative arrangements, the status quo will be assumed. A common view of the experience of combating the status quo within partnerships was described by one participant: “It's always an ongoing struggle to operate in that partnership from the stance of equity. There...was constant attempts on the part of...the mainstream able-bodied organization to take the fairly traditional role.” Her reference to the constant struggle to operate in a more equitable manner may be represented within a community partnership in the ways information is exchanged and decisions are made.
Participants spoke about the need to establish their own roles and terms of participation. As one participant said: "My mandate isn't to work for the city [the partner], my mandate is to work with the city for the consumers in this community...if they [other partners] don't respect your perspective and maintaining that perspective, then I think it's time to reassess the partnership." Her comment raises two major points: disability representatives should establish their own terms, roles and loyalties; if these terms are not accepted by others, then people with disabilities should consider leaving the partnership altogether. During the final workshop of this study, the participants and facilitators made constant reference to "door number three" to remind ourselves that our choices were not limited to choosing to participate and choosing to participate with conditions. People with disabilities can, at any time, choose to leave a partnership.

In fact, several participants described situations where participating in a community partnership may not be in the best interests of people with disabilities and their organizations. Participants made comments such as the following: "It's important to think carefully before entering a partnership to see if it is the right thing for you, your organization, and/or your issue." This is a particularly pertinent caution given that disability organizations are themselves struggling to survive government funding cutbacks and may not have the resources available to properly support a disability representative.

The need for thinking critically about partnerships was apparent in one participant's articulation of potential problems with partnerships: "partnerships can set people up, can set the community up...people who come from different parts of the community are getting tired of mainstream organizations entering into short-term partnerships that, after the money is gone, whatever, the service or whatever the initiative was that you were looking at doesn't happen because the mainstream organization doesn't have the commitment." Several participants described the personal and political commitment that is required on the
part of all people involved in order for community partnerships to result in mutual benefit and positive social change.

Making power explicit was a theme that arose from the study. Although not all participants preferred this approach, some participants found it effective to name the location of power and control. Other participants described the need to confront those that deny the existence of power issues within a community partnership. It has also been my experience that people with disabilities and members of other marginalized groups appreciate the Partnership Agreement Framework briefly described in Chapter 2 (Krogh, 1996). As a tool it forces people to make the power arrangements that underlie the essential pieces of the working relationship explicit. Through the process of making power explicit, people openly confront the challenges for rebuilding structures of power more equitably. Belief systems and social structures work to benefit some and exclude others; making this explicit is a powerful step in altering the relations of power.

Given the comments of the participants in this study, it would appear crucial for people with disabilities to apply a critical analysis of power to partnerships and determine whether it is in the best interest of people with disabilities and their organizations to participate in a proposed partnership. A central theme from the third workshop was choice for people with disabilities. Such a choice is to determine their own roles and terms and decide whether to leave the partnership if they feel that their participation is reinforcing the dominant relations of power rather than creating new opportunities for people with disabilities.
People who appear to be understanding of a disability perspective but who dismiss power differentials are imposing a form of oppression similar to that described by Bourdieu and Passeron (1977). In keeping with the work of Lorde (1984), people in dominant positions need to accept that there is a need for altering the relations of power before they can commit to creating change. In the case of people with disabilities, nondisabled people must accept that people with disabilities have historically been marginalized through the dominant notions and practices of people in society. Community partnerships present two possibilities with regard to power relations; one to reoppress and another to recreate.

**Limitations**

This study has several limitations related to the total number of participants and the ways in which they were selected to participate. The study was based primarily upon interviews with only 21 participants. During the first and second phases, the partner disability organization chose the participants to be involved in the workshops. Although several methods were used to recruit participants, there were likely biases in the selection process. The most significant bias that I observed was that this organization tended to involve representatives from other disability organizations that also used an Independent Living approach. Therefore, political advocacy organizations were excluded from the data generated from the participants in the first and second workshops. Workshop participants also volunteered to be interviewed for this study. This process may have also been biased. I suspect that those people who were interested in analyzing partnerships and who were concerned about power in
partnerships may have been more inclined to volunteer. For the third workshop, a number of criteria were employed during the selection process such as geographic representation, partnership issue, culture and gender. Although these were used to attempt to gather a diverse group, this group of 10 participants is too small to be considered representative along any of these dimensions.

At each of the three phases of the study, more women than men were involved. The first workshop on the topic of guardianship had many caregivers attending; people in this profession are mainly female. For the second workshop on partnership between disability organizations and women's organizations, the higher representation of women was deliberate and inevitable. More women than men were interested in participating in the third workshop, even though an equal number were recruited. In many cases these women were playing some form of leadership role in their communities. According to the comments that were made by participants, female leadership is not predominant in the disability movement. Female leaders perhaps demonstrated a greater level of interest in looking at power issues in partnerships than men.

Participants were representing their own experience and ideas about the involvement of people with disabilities in partnerships. The people interviewed from phases one and two were asked about their experiences and ideas of partnership that were generated from the workshop experience. They were also free to speak about any other experience that contributed to their understanding of partnerships. Participants from the third workshop either represented only their personal views or the views of a disability organization that they were affiliated with. Since people did not always
distinguish between personal and organizational viewpoints, I was not able to make this distinction. Therefore, although this third workshop did involve people who were involved in both political advocacy and Independent Living disability organizations, the comments cannot be clearly separated. The numbers are also too small for them to be considered representative of the views of disability officially held by the two types of organizations.

The intention of this study was to identify pertinent themes and generate possible conceptual relationships from qualitative data that would describe the experience of partnerships from the perspective of those involved in the study. It is crucial to reiterate that proportions and frequencies within the present samples cannot necessarily be extrapolated to the general population of disabled persons in Canada. Attempts to generalize findings should be approached with appropriate caution.

**Conclusions**

**Creating New Ways of Relating**

Partnerships can result in many different forms of benefits to individuals, groups and communities. These include opportunities for new learning, fostering respect, building trust, seeing the perspectives of others, as well as generating community development initiatives and innovative service delivery models. A relaxed atmosphere, the use of active listening and making power explicit were found to facilitate people's ability to examine their own attitudes and create new ideas by integrating the life-based expertise of others.
Several authors have called upon people to recognize their responsibilities in developing new ways of relating to one another that are more equitable (in other contexts, hooks, 1984; Freire, 1993; with specific reference to disability, Oliver, 1992). This requires the monitoring of one’s own beliefs and behavior and reassessing whether or not to continue to adopt practices and belief systems that effectively act to limit the power of certain groups of people.

Changing relations of power through community partnerships can be an extremely rewarding but challenging prospect. Participants in the third workshop discussed the need to put the process of social change in context. As one participant stated: “partnership needs to have enough time to find new ways to work together...we need to be gentle with ourselves, that this is ongoing work...sometimes we do get a bit impatient with the process.” Their message is relevant to all partners who struggle together to create something new in an environment of resistance.

Within partnerships that include people with disabilities, members are challenged to consider how they have come to understand disability and examine the limitations that this construction may be imposing on consumer participation. The practices within a partnership for information exchange, issue analysis and decision making that may have automatically developed from common-sense ideas, and the rules of institutions should be questioned and recreated in a manner that allows people with disabilities to participate without environmentally created handicaps.
Final Remarks

The struggle of disadvantaged groups to share in the rewards of society has been a long one. Issues related to obtaining power are complex and multilayered, since as I have shown, forms of discrimination are replicated within a particular group as well as in a broader societal context. Within all marginalized communities, including people with disabilities, there is a need to acknowledge and address the forces within and outside their group which act to perpetuate their subordination. As part of their efforts to create a more just society, methods for enhancing people's awareness of power in its various forms, it would appear, must continue.

The approach of this study represents a first step. My hope is that people with disabilities and disability organizations will continue to make their voices heard as they examine and address the inequities that exist within collaborative community partnerships. All partners, I hope, will not only accept responsibility for addressing power issues, but will consider adopting a vision of partnership as a potential site for creating new ways of relating.
References


Heron, J. (1996). Quality as primacy of the practical. *Qualitative Inquiry, 2*(1), 41-56.


Krogh, K., & Lindsay, P. (in press). Incorporating consumer perspectives into augmentative and alternative communication research methods. *Augmentative and Alternative Communication*.


APPENDIX A

Partnership Agreement Framework

(source: Krogh, 1996)

1. Principles, Beliefs, and Values
   - completing the partnership agreement may require a preliminary period of time
   - differences need to be acknowledged
   - a common set of guiding principles need to be established
   - these guiding principles need to be referred to on an ongoing basis

2. Objectives
   - common objectives need to be established
   - partner-specific objectives that do not compromise collective objectives need to be explored, possibly within a meeting of members of that partner group
   - partner-specific objectives need to be presented, acknowledged and agreed upon by all partners

3. Roles
   - roles need to be explored in order to look at the involvement of all partners in each stage of the research (or community project)
   - while involvement in a stage may not easily be determined or even desired, partners should be encouraged to explore the creation of new roles that would support the partner specific objectives, the collective objectives, and the guiding principles
4. Responsibilities

- each partner group and individual involved must ensure that the guiding principles of the group are reflected in their list of responsibilities, e.g., providing full-access accommodation
- the responsibilities of each partner group should be made explicit
- for people with disabilities, there may be responsibilities related to representation, such as reporting to the board of directors of a disability organization

5. Benefits and Acknowledgement of Contribution

- there are many way to acknowledge contributions; these should be explored and identified early in the process
- people's preferences for public or private acknowledgement should be respected

6. Supporting the Partnership Process

- resources (time, funds, attention) must be allocated toward fostering trust and mutual understanding among the partner groups
- the partnership agreement reflects a commitment to the partnership process and relationship

7. Conflict Resolution and Evaluation Mechanism

- investigators and participants are to prepare at the outset a means for resolving conflict should one arise demonstrating a recognition of how differences may lead to conflict but also a commitment to work through the challenges
- the evaluation mechanism should be regular and should include monitored follow-up activity
- both the conflict resolution and the evaluation mechanisms should be linked to the guiding principles
APPENDIX B

Sample Partnership Agreement

Refined and updated from March - December, 1995

Principles, Beliefs and Values

This project will be conducted in a manner that is consistent with:

a) The Independent Living Philosophy*
b) Academic Guidelines and Requirements
c) Ethical Procedures for Research

Objectives

Joint Objectives
• to learn about community-based partnerships
• to learn about the role/impact/activities of the (partner organization) in partnership building
• to learn about partnerships in research

(Partner Organization)
• to receive assistance with workshop evaluation

Kari Krogh
• to complete academic requirements

Roles

Joint Commitments
• to collaborate

(Partner Organization)
• the community-based partnership building activities of the (partner organization) will be a major source of information

Kari Krogh
• Kari will act as the principal researcher in the study that will be used for her thesis. (Reports etc. may involve input from others who have the time and interest)
• With mutual agreement, Kari will also take on additional roles, such as participant, participant observer, evaluator, and facilitator as appropriate
Responsibilities

Joint Responsibilities
- to review together and agree upon the informed consent for participants and administrative consent forms. An ethical review for the university must also take place.

(Partner Organization)
- to provide information needed for this research project (following ethical procedures, for example, confidentiality)

Kari Krogh
- to provide a brief written evaluation of the workshop by March 27, 1995 and a brief summary of workshop #2 by December 20, 1995

Finances
- Kari Krogh will not be paid by the (partner organization) for research work
- expenses related to the report and thesis such as phone interviews and transcription may be covered if the funds are available within the project budget
- expenses for research, evaluation, participation such as travel, will be covered by a variety of sources but the responsibility of research related expenses that go beyond the usual project costs will not be the responsibility of the (partner organization)

Benefits and Acknowledgements

This has been the topic of many discussions. The debate has been providing benefits to the (partner organization) while maintaining confidentiality of participants in workshops who might be identified if the (partner organization) was named/credited in the reporting of the research results. We have reconciled this by negotiating a role for Kari Krogh which provides direct benefits to the (partner organization) on a workshop by workshop basis. The research results of the thesis will not explicitly identify the (partner organization) in order to protect the anonymity and confidentiality of the participants who participated in interviews. This would be consistent with the university’s rules about confidentiality in research.

Through discussion we identified several ways in which efforts to maintain individual anonymity and confidentiality in addition to those outlined in the informed consent form, including:

a) I will be spending increasing amounts of time in the geographic area of the (partner organization) and I will become familiar with what kind of information may lead to the identification of a person. I can focus on
changing relevant information in their interviews like place of work or location of residence.

b) There will be significant time delay of more than one year before the information is published in a thesis.

Supporting the Partnership Process

The Partnership Agreement is being used as a tool to focus our discussion of partnership issues. To date we have been through several drafts and have involved many people linked to the works. We have taken the approach of continuously modifying the agreement as our activities give rise to new issues and as our understanding of the relationship and issues develop.

We will remain committed to open and regular communication.

The book, Independent Living and Participation in Research, produced by The Centre for Independent Living in Toronto (1992) will be available as a resource.

Conflict Resolution Mechanism

Our preference is to use consensus discussion to resolve conflicts. In the event that this is not successful, a third party, selected with mutual agreement, will be called upon to assist for a mutually agreed upon period of time. One individual who has been suggested for consideration is (name) who works in the local area and who has familiarity with Independent Living Philosophy. A contribution from the board for this service could be provided by the (partner organization) if approval from the board of directors in obtained. The cost for this service would ultimately be the responsibility of Kari Krogh.
Partnership Agreement

Date: _________________

signature: Kari Krogh, Graduate Student,
The Ontario Institute for Studies in Education of the University of
Toronto

Date: _________________

signature: (partner organization representative), (partner
organization)

Date: _________________

signature: (partner organization chair of the board of directors),
(partner organization)

Date: _________________

signature: Judith Wiener, Thesis Supervisor
The Ontario Institute for Studies in Education of the University of
Toronto
APPENDIX C

Sample Informed Consent Form

INFORMED CONSENT

1. What information will be collected?

Information will be gathered about people’s ideas about and experiences with community-based partnerships and their efforts to build such partnerships. The focus will be on partnerships that include people with disabilities and their representative organizations.

2. What will the information be used for?

The information will be used by two parties. The (name of research partner organization) will be provided with a report to share with (name of national women’s centre network) and the workshop participants. This brief report will include information from the workshop that summarizes the work of the group. It will not include any sensitive information with direct quotes unless permission for its use within the context of the report is specifically obtained.

Kari Krogh may use this information for academic purposes including a doctoral thesis and public sharing through conference presentation and publication. She is a graduate student at The Ontario Institute for Studies in Education of the University of Toronto.

3. What are the risks and benefits?

In addition to contributing to a vision of partnership between women’s groups and Independent Living Centres, you may personally benefit by being provided with an opportunity to express your opinion and reflect on your ideas.

There is a risk that a reader (for example, someone very familiar with the community, the ILRCs, and/or women’s centres) may be able to guess the identity of a particular person from personal stories even though no names will be used. However, there are five steps that will be taken to protect your identity (see below).

4. Can I stop participating?

You can choose to stop or limit your participation at any time.
5. What steps will be taken to keep information anonymous and confidential?

In this study, anonymity of participants is a priority. Although anonymity cannot be fully guaranteed, steps will be taken at each stage of the process to protect your anonymity, including the following:

i. Real names will not be used in any public sharing of the information. Transcripts of interviews and notes will also omit full real names and will use pseudonyms.

ii. Information other than names may be changed in order to protect identities of the participants, for example, names of places and names of professions. This will be done before any public sharing of the information in such a way as to not influence greatly the ideas and meanings communicated.

iii. The person hired to assist with the transcript preparation will be an individual who is not connected to either the women’s movement community or the disability movement community. This person will sign an agreement to maintain confidentiality.

iv. Personal information will be kept secure, confidential and locked. Raw data, such as actual transcripts will only be accessed by the researcher Kari Krogh. The initial analysis (without names) may be shared with Kari’s academic advisors, (name of representative from partner organizations) of the (name of partner organization) and or (name of coordinator from women’s centre involved) unless otherwise stated in conditions of participation.

v. OISE/UT will be involved in an ethical review before this information is used for academic purposes.

6. What if I have questions?

If you have any questions or if you would like to discuss the project, you can contact Kari Krogh at The Ontario Institute for Studies in Education of the University of Toronto (416) 923-6641 ext. 2414 or (name of research partner representative) at (name of research partner organization) (phone number).

7. Signing a Consent Form

Please sign the two forms and keep one for your records. If there are conditions that you would like to make regarding your participation, please specify them in the space provided.
This request has been made by:

Kari Krogh
Graduate Student
Department of Applied Psychology - 6th floor
The Ontario Institute for Studies in Education of the University of Toronto
252 Bloor Street West
Toronto, Ontario M5S 1V6
(416) 923-6641 ext. 2414 (phone)
(416) 926-4708 (fax)

CONSENT FORM

Dear Kari Krogh:

I understand the research project that I have been requested to participate in. I have been given a written copy of the information sheet and have had the materials reviewed in plain language with me verbally. I have been provided with an opportunity to ask questions. I understand that information will be collected and how it will be used. I also understand the benefits and risks to myself. I understand that I can withdraw from the study at any time. I have been informed of the safeguards in place to keep the information I provide confidential and anonymous. Finally, I have been provided with contact information so that I can ask questions in the future.

name (print):
address:
phone:
signature:

conditions/arrangements:
APPENDIX D
Sample Administrative Consent

Background Information

On behalf of the (name of partner organization), we understand that Kari Krogh who is a graduate student at The Ontario Institute for Studies in Education of the University of Toronto, will be using information gained from the “Building More Equitable Partnerships” workshop April 10-15, 1997 for research purposes. She will be conducting interviews with some participants and collecting additional information, without reference to names, from group discussions at the four-day partnership training workshop. Each person interviewed will be asked to review an information form and then sign an informed consent form prior to the interview. The (name of partner organization), Kari Krogh, and Beyond Consulting Inc. are the three partners involved in this partnership training workshop.

Information Collection and Use

We understand that information will be collected through interviews, participant observation, and workshop materials including flip chart notes. We also understand that the information may be used by Kari Krogh for various academic purposes including thesis, course work, and public sharing through conference and publication.

Risks and Benefits

The (name of partner organization) and Beyond Consulting Inc. may be named as organizing partners of this workshop. This information will not be disclosed if it is seen to threaten the desired confidentiality of participants. The (name of partner organization) and Beyond Consulting Inc. will benefit by having access to the summary report of the research findings. We understand that some evaluative information may be included in the research including that related to individual participants, institutions/organizations and the (name of partner organization).

On behalf of the (name of partner organization), we provide administrative consent for its involvement in this research.

_____________________________
(name of research partner representative), (position within organization)
(name of research partner organization)

_____________________________
(name of individual), Chairperson of the Board of Directors
(name of partner organization)
APPENDIX E
Sample Question Guide
Semi-Structured Interview Question Guide for First Workshop

Part I
1. Tell me about yourself. What is life like for you?
2. What have your experiences with inclusion/exclusion been?
3. What have your experiences with guardianship (workshop topic) been?
4. What have your experiences with partnership been?
5. How did you come to be involved in this workshop?

Part II
1. Please describe the workshop (objectives, participants, roles).
2. Please describe the inclusiveness or partnership approach of the workshop.
   probes:
   - how were people included?
   - similarities and differences among participants
3. How did you fit into this group?
   probes:
   - what did you see as your role/contribution?
   - were strengths appreciated or not by others?
   - did people’s attitudes change towards you or others?
4. Workshop
   a) Attitude Activity
      Which barrier did you pick (part of a specific workshop activity) and why?
   b) Others
      What did you learn from the others who were involved in the workshop?
   c) Evaluation Comments
      Can you tell me about the evaluative comments that you or others made during the workshop (provide a specific example of one of their comments)?
   d) My Role
      How was I perceived?
      probe:
      -please help me to learn about my influence on a group.

Part III
1. What was the impact of the inclusive nature of the workshop on you?
   probes:
   -what did you learn regarding partnerships, yourself, others?
   -what did others learn from you?
2. What was a positive impact of using this approach for addressing a community issue?
3. What was a negative impact of using this approach for addressing a community issue?
4. Would you think this approach would be good/bad for addressing other community issues?

5. Do you think your thoughts or actions might change as a result of this workshop experience? In what ways?
   
   probes:
   -the way the individual may approach life: home, community, work
   -concrete plans for the future contribution to the group and issue
   -do you think you’ll remain connected to the project?

6. Has this workshop experience been helpful in your thinking about the issue, yourself, your community or a group that you belong to?
APPENDIX F

Participant Descriptions from the Third Workshop

1. Anna was the executive director of a disability advocacy organization in a northern region of Canada. Her partnership project was to foster the establishment of a formal partnership with a collective of First Nations Communities. The purpose of the partnership, as initially conceived by Anna would be to share information and provide mutual support. She had previous experiences interacting with members of this community and was interested in strengthening the relationship.

2. Betty was a French-speaking woman who was employed at a disability organization that adhered to the Independent Living Philosophy. She was interested in reflecting on the challenges that she faced in building linkages between disability and seniors’ organizations, in order to build stronger partnerships in the future. The focus of their collective work was developing a curriculum on healthy living skills.

3. Claudia was the executive director of a disability advocacy organization. She was working on a large partnership involving government departments, social service agencies and development groups. This partnership had a mandate to address a range of issues including education, employment, social policy and socioeconomic development.

4. Dianne was an employee at a service agency that addresses concerns for people with developmental delay and their families. She was working on a partnership project during the past several years to develop a policy and legislative framework that would establish financial assistance based on individual need rather than a generic social assistance system. Dianne was interested in further developing a charter among the many partners involved to encourage long-term commitment after the formal funded period for the project ended.
5. Ema was a member of a self-advocacy organization for people who have developmental delay or learning-related disabilities. She was working on fostering better partnership relations between her organization and a service agency which tended to be operated by family members and service providers interested in supporting people with developmental disabilities (cognitive impairments). Ema was interested in building the organizations' understanding of one another so that they could work on issues that were of mutual concern.

6. Fabricio was employed by a community group that addresses the needs of Hispanic people. He was involved in implementing several programs related to people with disabilities. He was working on projects related to building partnerships among people who are from different cultural backgrounds, some of whom had disabilities.

7. Gerald was an employee of a disability research institute. He was working on a number of committees related to research and education. He was interested in applying his learning to his efforts to establish more equitable partnerships between academic researchers and people with disabilities.

8. Helen intended on applying her community plan in the various settings that she was involved in including a university, disability organization and women's centre. She was particularly interested in linking feminism with disability rights. She has a history of involvement with organizations that adhere to the Independent Living Philosophy.

9. Ingrid works as the executive director of a disability advocacy organization. She was working on developing a partnership between the core of the organization and small grass-roots committees that have developed to address issues at a local level.
10. Joanne was a board member of a disability advocacy organization. She was working in partnership with engineers, university professors and her consumer-driven disability organization to establish an institute specializing in the development of assistive technology for people with disabilities. She was particularly interested in establishing more formal guidelines for the fast-growing partnership that would describe roles, responsibilities, policies, and procedures.