EXAMINING PARTICIPATORY ACTION RESEARCH INVOLVING WOMEN WITH DISABILITIES: PARTNERSHIP, PERSPECTIVE AND POWER

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Examining Participatory Action Research Involving Women with Disabilities: Partnership, Perspective and Power

by

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ABSTRACT

Being a primary investigator in a participatory action research was the highlight of my graduate studies. The research involved women with disabilities, an academic, a community leader of a local disability organization and me, a woman with disabilities and a graduate student in Women's Studies. The research examined issues of employment and of knowledge of adaptive technology by women with disabilities. Adaptive technology is whatever hardware, software, or environmental adaptations a person needs to enable gain computer access.

As a secondary analysis this thesis takes the form of a case study that reflects back on the primary participatory action research initiative through critical discourse analysis. Feminist case study enables examination of social phenomena through an individual case rather than as a comparative analysis. Throughout the case study it becomes apparent issues of difference and representation arose that challenged varying historically constituted knowledges and practices located within both the disability organization and the university. This study answered the research question how do issues of difference and representation influence participatory action research process.

Data for this qualitative study involves portions of the ethical submission, personal correspondence, emails, journal entries written during the primary research and three sections of university policy. Each source of data through critical discourse analysis illustrates the impact of difference of perspective and issues of power within partnership.

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Graduate school is a whirlwind of classes, reading, thinking, reconfiguring, research and writing. Graduate studies demands pivotal life changes that extend beyond the personal, and into family and social spheres. This is why it is so essential to thank all of those who supported this endeavor. Many people have contributed to my efforts to achieve a post graduate degree, particularly my husband, Robert, son, Mike, and my mother, Doris. Individually each has responded positively their commitment to support my need for personal development, and intellectual growth. Thank you to friends Gemma Langor, Lanie Woodfine, and Barry Galloway for critiquing various sections. That family and friends have contributed in such a variety of ways I now realize achieving within graduate studies is indeed a community effort. Academic supervision comprises another section of the community effort. My thesis supervisors, Diana Gustafson and Roberta Hammett have offered support, and expertise, and for this I thank them both sincerely.

Twelve women with disabilities enabled the participatory action research from which this thesis is formulated. Their stories were profound, and often disturbing, and I thank the women for taking a risk, and sharing their experiences. Pivotal as well in this research, was the support of Donna Greene, Mary Reid, Barry Galloway, and the academic advisor who together with grounding and sustenance, pushed the primary research project into a positive space. A special thank you to everyone, who in one way or another, offered their support, and expertise, throughout the primary research.

Praxis came alive for me when Linda Cullum enlightened my world through the fascinating world of feminist theory. Opportunity to access Linda's mentorship has been an experience I will always cherish. Kate Bride is an educator who possesses a profound capacity to push the boundaries of how one might envision the everyday world and it has been a pleasure to be challenged by such thought. I have also enjoyed invitations from both of these women to present disability concepts in various Women's Studies classes. Thank you.

Within the meeting space of the Sally Davis Room is one small section of the Women's Studies community where I met friend Wanjiru Nderitu. Meeting and establishing a friendship with Wanjiru has been a blessing for which I am eternally grateful. Within this same room I have met Onar, other graduate students, faculty, and Joan. Thank you to the fabulous staff at the library and to Patrick, who offered his editing skills.

The final piece of what has been the construction of a fluid community that has supported me throughout the graduate years is funding for research from the Canadian Centre on Disability Studies, continued support from Memorial University of Newfoundland graduate assistantship and recognition from the national disability organization Canadian Association of Independent Living Centre's through the John Lord Award. This award is an acknowledgment of excellence in research that validates persons with disabilities and has appreciation for the Independent Living philosophy. In conclusion, I thank all of these people, philosophies, and support. I feel blessed for having had the experience.

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CHAPTER ONE

Introduction

The ways of knowing are inherently culture-bound and perspectival.

Patti Lather, 1988

Being a primary investigator in a participatory action research (PAR) was the highlight of my graduate studies. The research involved women with disabilities, an academic, a community leader of a local disability organization, a research assistant and me, a woman with disabilities and a graduate student in Women's Studies. The research examined issues of employment and knowledge of various types of adaptive technology among women with disabilities. Adaptive technology is whatever hardware, software, or environmental adaptations a person needs to enable them to gain computer access.

A launch marked completion of the research. People from the university and the disability organization came and celebrated. Just following the launch as I was preparing to begin this thesis I was speaking with an academic about the research topic. I was asked how, if I had concerns about the research process, could I have felt it appropriate to celebrate the project with a launch. Surprised by the question, I now realize the apparent contradiction. It may appear confusing, but an underlying assumption of feminist research states that improvement to the research process comes with reflection back on that process. It is critical that one removes the personal lens or perspectives of various roles in effort to glimpse a larger picture. Schratz and Walker write, "we need to find ways of turning our approach to research back on itself so that it becomes critically recursive, and we need to do this in ways that avoids falling into a downward spiral of infinite regression" (1995, p. 13). Thus my intent here is not to analyze data generated from a particular research initiative, described later in this chapter, but rather to study the participatory action research process.

Had I chosen to write about the primary research findings, this thesis would have had a very different look and feel. My problem with this approach was that despite the fact that I gained consent to do so, participants became accustomed to editing the tone and data of the report. A thesis is a work of one, supported by supervisors. One tenet of PAR is to always consider participant view, therefore, I was uncomfortable with the prospect of reworking participant data gathered specifically from a research designed for group work to gain a graduate degree. I am not suggesting this is a universal view or a standard but rather that it was my opinion at a given point in time.

Removing participant data from the equation leaves the researcher with the research process itself. Part of the risk or perceived risk of examining the research process is the alienation of others involved, such as the co-investigators and/or participants. This is because the analysis within this thesis represents a personal perspective that focuses on roles rather than on specific individuals. Thus, this thesis is about perspectives, not people. It is about challenges that arise when one is working within an approach to research that focuses on power, representation and difference and how these issues impacted on one participatory action research process.

This thesis answers the research question, how do issues of difference and representation influence the participatory action process. Each of the seven chapters addresses a different aspect of these issues. This first introductory chapter describes key approaches to this secondary research, places me, the writer into the conversation by provision of background information, and describes the primary research.

1.0 Feminist Methodology

Key to feminist research methodology is the enhancement of knowledge and social justice through a wide variety of feminist methods that concentrate specifically on respecting the needs of women and other disadvantaged groups (Harding & Norberg, 2005). Participatory action research methods work well with feminist perspectives. PAR is an emergent approach to research that strives to address issues of social justice, social inclusion and exclusion, and the need for social change (Gatenby & Humphries, 2000; Morris, 2002). It focuses on participant involvement, raising the social consciousness by highlighting the value of the lived experience and making space for voices often omitted from dominant discourse (Kesby, 2005; Hall, 2005). Some researchers focus more on participant ownership of the research as a means to achieve social justice and change. This ideal, according to Kesby (2005), attempts to shed the layers of patriarchal conditioning found in other forms of more traditional research, penetrating beneath well established layers for that which is hidden below so as to traverse the line between theory and practice. Kesby writes, "[participatory approaches] aspire to reduce and circumvent the power relations normally involved in research and development and to take the notion of giving the marginalized a voice to new levels of facilitating their involvement in the design, implementation and outcomes of programs" (p. 2037). Participants gain control of power (at least theoretically) as they become involved in three keys areas of the research process, design, implementation, and the outcomes. Deconstruction of power imbalances occurs when participants and researchers share control, risk, and mutual disclosure in an effort to shed traditional research formats (Reinharz, 1992).

As a secondary analysis, this thesis is a case study that reflects back on the primary PAR initiative. Feminist case studies enable examination of social phenomena through an individual case study rather than as a comparative analysis (Reinharz, 1992; Padula & Miller, 1999). Stark and Torrance claim that, "[a] case study assumes that 'social reality' is created through social interaction, albeit situated in particular contexts and histories, and seeks to identify and describe before trying to analyze and theorize" (2005, p. 33). The framework of history and social discourse described throughout this case study links to the synthesis of the data.

A reflective analysis generates insight gained by critically analyzing and evaluating completed work (Hall & Hall, 1996). Mauthner and Doucet (1998) write "[r]reflexivity means reflecting upon and understanding our own personal, political and intellectual autobiographies as researchers making explicit where we are located in relation to our research respondents" (p. 121). Thus, the case study reflects back on the PAR and examines issues of power, partnership, and perspective. Perspective is directly associated with the ways discourse produces meanings depending on one's historically constituted knowledges and practices.

Discourse refers to an interrelated "system of statements which cohere around common meanings and values that are a product of social factors, of powers and practices, rather than an individual's set of ideas" (Holloway, 1984, p. 231). It is the way language is used as a form of expression (McGregor, 2003). Discourse speaks to the ways in which cultures, societies, groups, or historical periods construct meanings and these meanings are not static but rather ever changing. Barbara Johnstone (2002) writes of discourse as "communication in the medium of language… [originating in the form of a] mass noun" (p, 3). Johnstone conceptualizes the concept of discourse as one would the broad topic of music or information. While there are many styles and forms of music/information, both are thought of as a larger concept. In this context discourse relies on memories, information exchanges, or a generalization of what words may mean. Thus, discourse becomes what we think we know and how this knowledge is applied or transferred. According to Johnstone approaching discourse analysis as a singular noun differs from the approaches taken from those influenced by the works of Foucault.

Chris Weedon (1997) uses less of a linguistic focus in her approach to discourse. In this approach, discourse becomes a count noun (meaning it can be singular and plural). She uses the word discourse as a pattern of beliefs and action that arise from language. In this sense, discourses are "ubiquitous ways of knowing, valuing, and experiencing the world. Discourses can be used for an assertion of power and knowledge, and they can be used for resistance and critique" (McGregor, 2003, paragraph 5). The approach taken for this case study is to examine discourse in a less linguistic fashion and more broadly in terms of power and authority through critical discourse analysis.

Critical discourse analysis necessitates unpacking traditional notions, challenging what we believe to be true, and envisioning forces of power that regulate our beliefs. (Rogers, Malancharuvil-Berkes, Mosley, Hui, and Joseph write "[it is] a cultural tool [that] mediates relationships of power and privilege in social interactions, institutions, and bodies of knowledge" (2005, p. 367). Essential to critical discourse analysis is who benefits and who does not benefit from the way something is written or presented (McGregor, 2003). This case study utilizes a feminist approach to critical discourse analysis as an instrument to deconstruct discourse that sustains the patriarchal social order that privileges one group over another.

This thesis reflects my perspective, I do not presume to either represent the views of everyone involved in the primary research or speak for all women with disabilities. My position cannot be portrayed as neutral, because it is essential that I acknowledge my past life experiences, my own encounter with and understandings of disability, and life as a graduate student and researcher. For these reasons I continue this chapter with a short personal narrative that, albeit selectively, places me within the conversation. Following this is a detailed description of the primary research from which this case study stems. One of the co-investigators is employed by an organization that operates by an Independent Living philosophy and the final section of this chapter describes the principles behind this philosophy.

1.2 Temporary Space within the University

The introductory quote by Patti Lather states that ways of knowing are inherently culture-bound and perspectival (1988, p. 570). This alludes to the value of one's lived experience as a conduit for creating change and brings to the research a new way to view a situation beyond what has historically been accepted as the right way.

Within feminist methodology, the writer is not located from an assumed neutral position; therefore, such an approach situates the writer with use of the word 'I' within the text (Fonow and Cook, 2005). Fonow and Cook write, "understanding the role of the feminist researcher as an active agent in constructing knowledge has generated a large body of knowledge of reflexive writing and reminiscences about the motivation, interpretation, and process of doing research, and producing scholarship" (p. 2219). Situating the writer acknowledges that the writer is no longer presumed innocent and thus is no longer viewed as 'impartial,' while revealing the voice of the oppressed (Lather, 2001). As a graduate student whose self-identify includes having disabilities I have included a brief narrative about myself so that my position is at least partially exposed.

Before I became ill, I was an intensive care nurse. Most days I enjoyed my work and still to this day maintain relationships with some of the parents of the very small infants I had opportunity to care for. Over time the ravages of medication induced a litany of illnesses and mobility impairment which forced me to forgo many milestones taken for granted such as ideas of increasing my family, travelling, and working. As I had great difficulty breathing, I spent most of my days and nights sitting rigidly upright in my chair at home. This transition from an active worker, wife, mother, daughter, sister, friend, and so on into what the medical system termed a complicated case was difficult.

Various people I knew would call enquiring what I did all day long; I am told illness is not an occupation. I was persistently asked, usually under the guise of humour, what was happening on ‘the soaps’, which I had never watched in my life. Despite the fragility of my health, I felt guilty about being unable to work. My own feelings supplemented externally by those around me contributed an intense sense of failure and a fear of aimless existence ‘alone’ in my home. Once before, I spoke aloud of this fear and was told by another woman with a disability that I was painting a poor picture of being at home. It is my personal experience that being unwell, losing the stability of an earned income, becoming socially isolated, and being unable to make long term plans has not been positive. However, this fear, or perhaps phobia has been somewhat diminished with the advent of the computer and the availability of university distance learning programs because, within the computer the limitations of the body are less socially apparent. Thus, there is an opportunity to re-enter a space void of the social label of disability.

I viewed student life as a process whereby one attends classes surrounded by peers and a workload of four or five courses. However, this has never been my experience through distance learning and one or two courses at a time I left behind illness, breathlessness, and my wheelchair and immersed myself into hours of reading, thought, and writing. In the surreal world of distance education few were aware of my sickness so educators had no idea my health was correspondingly deteriorating with each course I took. That is not to say that the deterioration was a result of the stress from the courses, but rather a result of prolonged use of hazardous medications and a combination of illnesses. When I began to accept the improbability of returning to twelve hour shifts of nursing work, I focused on adult education, which was an area of study more available through distance courses.

Losing my job position due to illness was a significant milestone and not one that I found easy to cope with. I still have incredibly realistic dreams in which I am working shifts as a nurse. However, despite these dreams, over time I find I no longer fit into conversations with my nursing friends, and have come to realize that I have to move on. I decided it was time to embrace this new phase of my life and sought out other women with disabilities. I found other women with disabilities at the Centre. The Centre is a pseudonym for a place that provides services for women, men, and children with disabilities.

The word *disability* is a fluid term used by mainstream forces to differentiate between bodies and/or minds that are impaired, or deemed different in some manner from the majority of other bodies and minds in society. I do not use any definition for the word disability, because I have yet to come across one that adequately reflects the full magnitude of the oppression and body/mind impairment. It is my experience that those who readily supply the definition generally do not have a disability.

The phrase '*disability community*' is used cautiously (within this thesis) to reflect a group of individuals, and supporters of individuals, who electively and collectively identify with the social designation of disabled. Disability community is a phrase commonly used by disability service organizations in an effort to place themselves outside the domains of authoritative structures, such as governmental agencies and medical authorities. The Centre represents a small section of the disability community.

The first day I visited the Centre, I had an appointment with an outspoken community activist. I told her proudly that I was once a nurse, and she leaned into the table and somewhat jokingly replied that she would not hold it against me, but that I should not tell too many people. Taken aback by her remark it was some time before I understood how much medical influences have impacted the lives of women and men with disabilities. The woman gave me the book *Nothing About Us Without Us*, by James Charlton (1998). In the second paragraph of the book Charlton writes, "the scant attempts to theorize the conditions of everyday life for people with disabilities are either incomplete or fundamentally flawed as a result of the medicalization/depoliticization of disability" (p. ix). My personal experiences, self realization, and authors such as Charlton and Carol Thomas (2004, 2002, 2001, 1999) changed my perspective on many things in my life. Armed with some knowledge of disability issues, I decided to enter graduate school, specifically the Women's Studies Programme, for more intensive study.

Independent work and irregular self-set study hours have suited my body as bouts of illness go unnoticed. My desire to place myself, not necessarily physically, beyond the home was relentlessly fuelled my progress through the curriculum. I have now reached the point where my focus is to write what I believe will adequately add to the voices of women with disabilities. With all of this said, this thesis is not about me; it is about the working relation of a whole group of individuals, of whom I am just one.

The following section depicts my perspective of the research project; acknowledging that if any of the others involved in the research were to write an overview from their perspective, the product would likely be very different.

1.3 The Primary Research Project

Early in April 2004, I phoned the executive director of the Centre, who is a friend I have come to know because of my volunteer involvement with the organization. I informed her that I wanted to do some type of summer project involving the Centre. She replied several days later with a notice of a request for proposals for a small grant award. Issuing this request was a national disability organization closely affiliated with a Canadian university.

Upon close examination it appeared that information dispersed by the national organization suggested that one goal of the research was to link people with disabilities with the academia in an effort to do community-based research. I knew someone in the university I thought would be interested in such an endeavour, and mentioned to this person that I wanted to apply for the grant. It is vital to point out here that time lines were very tight, and it is remarkable that this individual agreed to engage in the effort. Both the academic, and the community, contacts supported me in the submission of a research proposal.

Commencing in June 2004, my research continued until its completion in August 2005. The application for the grant set the parameters of the initial research team. Initially the team consisted of three individuals; the university contact was the academic co-investigator, the Executive Director of the Centre was the community co-investigator, and I was the primary investigator.

Consultation with community contacts formulated the research topic, which focused on women with disabilities, employment, and adaptive technology. The funding agency stipulated that preference would be given to applicants who applied participatory approaches to their research, and also that an ethics submission was required before funds would be released. As a Women's Studies student, I wanted the research to have a gendered lens. Although not discussed at great length, I felt as if the idea of a gendered research project was not an idea that was well received by the Centre. The Centre operates on a philosophy that advocates the use of the action word 'consumer,' rather than what some would perceived to be the more passive words patient or client. "Consumer" denotes the person with the lived experience of disability, and suggests an individual capable of controlling her own life experiences, making informed choices, taking risks with the choices made, and being responsible for those choices. For this philosophy to be successful the consumer requires adequate access to disability supports. However, in an effort to shed identification of individuals with disabilities by disease, and to gain a "people first" strategy the disability rights movement has promoted the supposedly gender neutral term *person* with a disability. Within the landscape of this universality, the term woman or man becomes an uncommon utterance. As a result of this terminology women and men with disabilities have gradually evolved into 'gender less' beings or, to use a term coined by Rosemarie Garland-Thomson, as "asexual objects" (2002).

Traditionally, the disability movement has ignored other oppression such as gender (Garland-Thomson, 2002; Ferri & Gregg, 1998). That is not to say women and men with disabilities are 'gender less,' but rather that the historical tendency has been to discuss disability absent of gender distinction. The problem with this lack of gendered consideration is that the disability movement becomes, in a sense a sexist movement (Ferri & Gregg, 1998). During a conversation at the Centre, some staff and consumers said they thought it was exclusionary that my research project did not include men. On occasion, men visiting the Centre would stop me and say that they were signing up to participate in the research project. Over time this attitude has very much changed and there are now a few topics addressed according to gender (including a women's group and a men's group).

The university and the funding agency standards required an ethical submission before research could began (Appendix B). In August 2004, an ethical submission was completed. Parts of the ethical submission such as the university's description of a vulnerable participant and some of the language used within the ethical submission were bothersome to the community co-investigator. The community co-investigator preferred the terms ‘researcher’ and ‘partners,’ rather than ‘primary investigator’ and ‘co-investigators’, which the academic co-investigator thought to be more in keeping with university research standards. For whatever reasons, the community co-investigator, who had initially revised the ethical submission, stopped responding to other revisions and, while I was aware of this I did not explore the issue in great detail. The value of words, how we identify ourselves, and how others identify us lies in discussions held throughout the following chapters. Community challenges to words, and meanings of words, are discussed further in Chapter 6.

As the ethical submission was taking form, the community co-investigator drew up an agreement that was to govern relations between the Centre and myself throughout the research. Several times we revised the form before sending it on to the academic co-investigator, who returned to us with still more revisions. The community co-investigator reviewed these revisions and never referred to the agreement again.

In October of 2004, I had been a member of the Board of Directors of the Centre for four years. The academic co-investigator and I discussed how my Board position might be regarded by the ethics review committee of the university as a real or perceived conflict of interest. Upon her advice I submitted my resignation to the Board, which caused a great turmoil. The Board expressed its disagreement with my resignation and, upon the advice of the academic co-investigator and others from the university, I subsequently withdrew it. This action appeased the Board, and instead of resigning I agreed to update the Board every month as to the progress of the study, and to keep the academic co-investigator informed should any problems arise. Further discussion about how this unfolded can be found in Chapter 6.

While there was communication between the two co-investigators and myself, there was little three way communication. This may be due to the fact that the co-investigators and I only met several times throughout the project, and the entire team, including participants, never met. I spent considerable time at the Centre, so there was frequent contact there with the community investigator. The academic co-investigator was readily available to me via e-mail, so most communication between the co-investigators was conducted through me, the primary investigator.

In November 2004, it became apparent that it was unlikely the university would manage the funds for the project as I had anticipated. Transportation with the disability transit system is a flat $5.00 return fare, while the university reimburses transportation at a set rate based on miles travelled. This could reflect the difference in that consumers of the Centre predominately use the Para transit system, while many people at the university have access to a car. As a result, some participants, through the university system of reimbursement, would not have their transportation costs covered. Some lived close to the centre, but still required transportation. Several other issues conflicted with the university system of fund management, so the advice of the Research Officer was to have the funds managed, by me, through the Centre. This arrangement worked well until later, when I became aware of the repercussions of this choice. Further discussion continues in Chapter 5.

With the ethical submission approved and the funding determined, it was time to recruit participants (Appendix A). The academic co-investigator suggested involving 6-8 participants, because this number would generate sufficient data and constitute a manageable workload for a master's level student doing qualitative research. The community co-investigator disagreed, and wanted a larger group. For various reasons, all of the twelve women who applied, took part in the research though our approach to participant recruitment was revised over time. More discussion about participant selection involving women with disabilities, can be found in Chapter 5.

The twelve participants were diverse in age, type of disability, work experience, and knowledge of adaptive technology. During December 2004 and January 2005, participants, the research assistant, and I attended one two-hour, and one five-hour, focus group sessions, as well as one two-hour adaptive technology workshop. It was tentatively planned that the participants would attend three, two-hour focus group sessions, and one two-hour adaptive technology workshop. After the first group interview session participants stated the sessions were too short and changed the format to include an adaptive technology workshop, and one more five hour session per participant, with the group split in half. One participant, unable to attend the longer session, requested and received a three hour personal interview.

The small grants award paid participant honoraria, childcare expenses, a lunch during the 5 hour session, and transportation up to five dollars for each meeting (See Appendix A). Participants expressed a desire to meet more often, but the limited research budget did not permit more meetings.

Six months prior to this in July 2004, the community co-investigator and I met with officials of the federal government, Human Resources and Skills Development Canada Department, and secured funds for a research assistant position. This wonderfully committed research assistant began work in December 2004, continuing until August 2005. The research team was now complete with twelve participants, one academic co-investigator, and one community co-investigator, one research assistant, and me.

The research assistant and I attended group interview sessions and the workshop. The research assistant had specific tasks to complete, including note taking during the focus group sessions, transcription of focus group tape recordings, providing Braille when required, designing the statistical charts for the final report, proofing drafts, and maintaining the project web site. I provided all written material that went into the reports and onto the web site, as providing accessible materials was a mandate of the project. The web site, now maintained by the Centre, is accessible to all people including those who are blind/visually impaired.

Primary data collection was completed via group interview sessions, a personal interview, the adaptive technology workshop, changes to transcripts, and e-mails. Data collection happened in part through the focus group sessions, enabling inclusion and sharing of any disability accommodations. Participant information was collected and was than compared to information found in government documents that focused on disability, employment, and education. Throughout the remainder of the winter and the spring of 2005 participants communicated frequently to me through e-mail, in person, and by phone. Everyone involved in the research, participants, the academic co-investigator, the community co-investigator, the research assistant, and I, had opportunity to edit the report drafts.

Participants received and edited all report documents in the communication format of their choice. Examples of alternate communication formats include Braille, plain language, and .doc formats. During editing, participants removed or changed information that they contributed that was either inaccurate or misunderstood by me. Some regularly edited their own material, while others commented only at times, and one or two made no commentary at all. Some spent considerable time editing but often their responses would take weeks to be completed. This was challenging when so many people were involved in the editing, as a deadline was forever looming. Deadlines included a completion date set by the funding agency, respect for the time of the participants and the co-investigators, my need to write a thesis in a timely fashion, and the end of the research assistant's position.

In May of 2005, participants gathered and commented on what was tentatively one of the last drafts of the report, but in reality more drafts followed until the end of July 2005. We still had to selected a report format, so we began to examine our choices. One in particular, consisted of one double-sided page summary for participants, a four page summary with information aimed at academic readers, and a six page summary providing ample statistical data, as preferred by the government. Supplementary to this type of report style was a thesis style document. While the summary page style of report was appealing to both co-investigators, and some people around the Centre, all of the participants rejected it. They stated that such a report was hierarchal in nature and presumed the participant would require less information than others. Thus, the search for other report styles continued, though, because the group was working from multiple of equally important perspectives, over time it was difficult to agree on the format of the final report. Gradually, it seemed necessary to produce two types of report documents, each with various formats of communication such as Duxbury (Braille) and plain language.

The plan was that the research assistant, along with some people who are well versed in the format of plain language, would develop this report document. Plain language, as I understand it, takes the message within a sentence and ensures that it is understandable in every day language. This concept strives to limit a sentence to just one concept, and strives to limit each paragraph to 5 to 6 sentences. The initial arrangement for plain language did not work, as sentences began to stray dramatically from the intended meaning. The academic co-investigator offered to have the report formatted but the community co-investigator informed me that this was the domain of the Centre and supplied a staff person to assist me with the work. Realizing that this could become an issue with the potential to dramatically delay the completion of the report; I decided that it would be in the best interests of the project to get the Centre staff person to help, and the academic co-investigator expressed no concerns with my decision.

The Summary Report is a visually appealing twenty-five page report with coloured pictures and summary writings. Good graphics layout and design took a sizeable portion of the funds, but provided a summary document similar to the type used by the University. Because the bulk of money was spent producing this report, and because several participants were blind/visually impaired and unable to appreciate this form of communication, a tactile of our project logo was included on the inside cover page. A tactile is a particular kind of paper that rises up when baked in a piece of machinery; this raised portion of the paper can be read by feel, and by vision.

The Full report was a text document much in keeping with standard academic thesis formatting. It expanded on the concepts briefly addressed in the summary, and also contained a tactile. A compact disk that contained various formats of communication such as Duxbury (Braille), plain language, and electronic text documents was affixed to all reports. It was imperative that reports be fully accessible, not only to women who participated in the research, but to any individual who wished access to the information. The research assistant formatted each compact disk, and ensured the web page met the standards of accessibility used by the Centre.

From this year-long experience, four points of interest have been purposively selected to form the analysis piece of this case study. These four points articulate the difference between varying historically constituted knowledge and practices. Thus, exemplifying different perspectives, issues of power, representation, and difference. These four points are:

1. Participant Selection
2. Negotiating the Rules of Financial Management
3. Ethical Concerns and Community Resistance
4. Varying Interpretations of University Research Policy

In summary, my primary research took place from June, 2004 to August, 2005. I have provided a very frank discussion about various challenges that were experienced throughout the year, but despite this critique the project was well received. It was recognized with a national award for its participatory approaches, and respect for the Independent Living, a philosophy promoted by the Centre. The Independent Living philosophy is a consumer -based approach to disability issues. This philosophy gained strength in Canada during the second wave feminist movement. I believe the partnership with Centre, steeped in this way of thinking, had a great impact on the relationships formed throughout the project. The following section provides further insight into this philosophy.

1.4 The History and Philosophy of the Independent Living Movement

In part, representations of disability issues are historical and, in modern times, connected to the evolution of the Independent Living philosophy. The Independent Living philosophy is one approach to disability issues found amongst individuals and organizations. It demands consumer control, respect, risk taking, and the right to have choice. Many participants and representatives of the Centre came to the research process familiar with the Independent Living philosophy and this influence was an undertone throughout the research.

This historical rendition of disability begins with the Disability Rights Movement, though I am not suggesting that this is the earliest history of disability. Selected is a point in time that uses a language to identify an era specifically devoted to addressing disability-related concerns. Prior to the Disability Rights Movement in North America support for people with disabilities was provided by individual groups that tended to focus on specific diseases or illnesses (Albrecht, 2002). When disability groups and individuals with disabilities united under a common voice the activists described their plight in society as being the result of socially constructed discriminatory practices, rather than as derived from their own body and/or mind impairment (Hughes, 2005; Thomas, 2002, 1999). This change in perspective provided a notable shift in thinking. Hughes (2002) pinpoints social discrimination that did not support the needs of some in society whose needs differed from those of the majority. He writes that, "the ontological essence of disability was transformed from a physical or mental deficit into a matter of discrimination" (2002, p. 64).

Disability Rights Movement activist, Ed Roberts, was instrumental in challenging barriers to Independent Living (Charlton, 1998; Zames Fleischer and Zames, 2001; Enns 2003; Enns and Neufeldt, 2003; Phillips, 2003). When denied entry based on inaccessibility of the campus, Roberts' legally challenged his right to attend Berkeley University, California, United States of America (Zames Fleischer and Zames, 2001). His legal challenges were successful, and gradually, with the support of other injured veterans, the university began to accommodate students with disabilities. As a result of Roberts' out-spoken and unrelenting challenges in the United States, Berkeley University became one of the power houses of the Independent Living Movement. Roberts' challenge to American universities to become wheelchair accessible resulted in ground breaking work that supported the entry of women and men with disabilities into higher levels of education.

Canada was also part of the evolution, as some injured World War II veterans became disability activists. One such veteran was Tony Mann, the Executive Director of the Canadian Paraplegic Association Western Division. He was instrumental in challenging the concept of exclusion as he highlighted the lack of physical accessibility to public places in Canadian society. His efforts did not happen in isolation, he had strong support from other Canadian activists. Over time Mann, and others, influenced issues such as building accessibility. Many people, such as Mann, dedicated large portions of their life to systematically chipping away at the aforementioned patriarchal structures in an effort to promote public and governmental awareness of disability issues (Ringaert, 2003).

However, not all women and men with disabilities ascribe to the Independent Living philosophy. The Independent Living philosophy, which appeals to some people with disabilities, emerged from the disability rights movement. Fundamental to the evolving Disability Rights Movement was the acknowledgement of Human Rights and full inclusion of people with disabilities within society (Enns, 2003). In a government report full inclusion or citizenship is described as, "… the inclusion of persons with disabilities in all aspects of Canadian society- the ability of a person to be actively involved with their community" (Federal, Provincial and Territorial Ministers Responsible for Social Services, 2000, p. 7). In effort to be actively involved, society must first recognize the barriers that support the exclusion of individuals with disabilities.

Activists challenged a political system that traditionally ignored people with disabilities, to become more politically aware of issues of exclusion. The act of self organization resulted in a resistance to traditional political values, such as the segregation of disability within mainstream society through institutionalization, resistance to labour market entry, and enforced poverty (Thomas, 2002). Their demand was not for political regulation but rather for a system that provided supports so that an individual could become self sufficient and speak for her or him self rather than having their opinions inaccurately represented by a third person expert. The individual with the disability is in a better position to determine need than the typical social 'experts' such as physicians and rehabilitation specialists (Hughes, 2002). A basic tenet of the Independent Living philosophy was that a greater number of people with disabilities could live independent lives if they were provided with adequate disability-related supports. Bringing this lack of social support to the fore, linked disability with oppression. The value of this link was that activists could argue that social attitudes and values greatly contribute to the exclusion of people who carry the label of disability. The link also brings into question *who* has the authority to determine disablement. The evolution of this philosophy has greatly impacted not only the lives of people with disabilities, but has projected disability rights as equal to the rights enjoyed by others.

Such changes have not taken place easily, and necessitate constant vigilance and protest. For example, it has been many years since Roberts first took action; yet, many Canadian universities are still not physically accessible to women and men with disabilities. Such physical barriers have restricted the entry of many women with disabilities into universities, and therefore, into academic research. Historically, disability issues have not been included in academic work. Finding methods of research that directly acknowledged the voice of the person with the lived experience resulted in the overwhelming support of sectors of the disability community to promote participatory approaches to research (Morris, 2002). Academics, such as Morris, have promoted PAR within the disability community, and in partnership with academics, as a means to authenticate one's voice in research.

1.5 Summary

This first chapter describes the approach I have taken to create a discourse analysis. Feminist critical discourse analysis is used to examine paradigms of power and social injustices through the application of fundamental values of feminist methodology. It is a method of research supported by academics and activists who wish to explore, understand, and ultimately influence the consequences of social oppression, dominance, and inequity (Lazar, 2004).

This Chapter describes how I am situated within the writing. It also outlines major sections of my research project. That the project was well received by those within and outside of the research, speaks to a job well done. However, the work is still incomplete. The complexities in many ways actually start here, because now it is time to look at the process; what worked, and what did not work. It is a complex process to provide voice to marginalized groups and therefore challenge the inherent forces that help us to make sense out of that which we know (Standing, 1998). Kay Standing writes, "if part of our role as feminist academics is to challenge academic conventions which exclude and marginalize groups, how can we hope to do this if we 'play by the rules?' (p. 197). Standing is referring to the difficulty of constructing feminist models of research within the traditional academic sphere, so that while flexible, these models must in some way support traditional principles of research and partnership.

Despite the fact that one can read, and conceptualize the theoretical value of feminist research methods, it is different to work within such parameters because of the unexpected, and at times expected, challenges one faces when trying to design research that fits within a variety of spectrums. The feminist critical discourse analysis I undertake here reflects back on one specific participatory action research process, and addresses some issues difference, and representation that arose. The value of this research question is that such discussion offers insight into the challenges of including the marginalized voice in participatory approaches to research.

1.6 Roadmap

Chapter 2 presents feminist methodology used throughout the research, elucidates my understanding of critical discourse analysis, and depicts the potential benefits and limitations of case study and methodology. Chapter 3 speaks about issues of difference and representation experienced by women with disabilities. The value of this chapter is that it sets the framework for further discussion about disability oppression. Chapter 4 illustrates a detailed exploration of PAR, what works and what does not work. PAR represents powerful approaches to research that promote partnerships that strive to evoke social justice and social change. Chapter 5 and Chapter 6 highlight selected data which is examined by critical discourse analysis. Specifically I examine: participant selection, who should control the research funds, problems with the dual position of being on the Centre's Board of Directors and a primary investigator, community resistance to academic advice, and finally varying interpretations of university research policy. The final Chapter, summarizes how issues of difference and representation do influence participatory action research.

CHAPTER 2

Methodology: How the Case Study is Constructed

Our words are never neutral. Fiske, 1994

Participatory approaches to research describe the primary research project introduced in Chapter 1. This case study reflects back on that process using critical discourse analysis. Feminist critical discourse analysis is an intricate multi disciplinary method of research that examines paradigms of power and social injustice through the application of fundamental values of feminist methodology. Foundations for feminist critical discourse analysis developed considerably with the advancement of post structural theories (Lazar, 2004).

This chapter presents some of the fundamental features of feminist methodology and addresses briefly concepts of post structuralism and disability feminism. Also described within this chapter is the framework for feminist critical discourse analysis, the case study; its benefits, its limitations, and its methods of data collection.

2.1 The Broad Spectrum of Feminist Methodology

About thirty years ago, civil rights activists and equality seeking organizations became aware of weaknesses in traditional research and its effects on public knowledge and social policy (Cunningham, 1993; Pratte, 1988; Hess, 1968; Rossi, 1973; Suchman, 1968). Which resulted in a widespread demand to reshape research (Brooks & Watkins, 1994). Traditional methods provided few of the much needed answers about a wide variety of issues, including, but are not limited to, the expanding poverty gap, single parenting, and widening trends of income inequality. Claims began to arise that suggested conventional science and researchers had disregarded differences amongst people, diversity amongst groups of peoples, societal inequities, the impact of a global economy, the deterioration of the environment, and other ways of knowing and knowledge production (Brooks & Watkins, 1994).

Feminist theorizing challenged dominant ideals by listening to and valuing what women had to say. Dorothy Mackeracher (2004) writes, "the second wave [of feminism] has challenged the dominant knowledge system by pointing out its limitations, particularly with regard to life experiences of women" (p. 200). Traditionally, patriarchal systems of knowledge production ignored or reinvented women's experiences. The result was that academic feminists challenged research produced by patriarchal discourse. Discourse is the methodology of giving meaning to communication, though discourse does not consider the possibilities of other ways of thinking or doing, but rather assumes a right way of doing or knowing through the guise of common sense. This more rigid traditional approach supports existing power relations and authorities (Gavey, 1989).

Oakley (2000) describes a second wave feminist movement as coinciding with a parallel movement within the academia to challenge overall traditional research methods and ways of knowing. She describes discrepancies in gender whereby 'statistics and men'are more valued and closer to the truth than the 'in-depth interview technique and women.' Women claimed discrepancies in the traditional valuing of men's way of knowing the world resulted in less respect for the perspective of women (Oakley, 2000). Oakley writes, "arguments against the 'quantitative' paradigm quickly became an established part of the feminist 'case' " (p. 33). She uses the word 'paradigm' in the context of a set of standards which a researcher can use as reference material. In this manner paradigms contribute to research processes and binding people together in mutual commitment. In contrast with traditional approaches to research, feminists demanded space be made for marginalized voices, necessitating changes in the overall approach to research methodology. Feminist studies evolved as a means to improve the world around us by challenging the hidden patriarchal forces that marginalize our value as women in society (Maynard, 1994). Thus, research within the feminist perspective is described as a more fluid organization of theoretical ideals, and from which academics can formulate particular assumptions.

My background as a student immersed in the nuances of feminist methodology and a disability activist supported the value of a feminist approach to research. However, it is my experience that the added perspective of disability studies is usually missing in feminist conversation, a claim similar to those of Black feminists. Further explored in Chapter 2, are the perspectives of Black American feminists, particularly, bell hooks (1992) and Patricia Hill Collins (2005; 1999).

Finding reference material that chronicles an extensive history about women with disabilities is difficult (Borsay, 2002). Some possible explanations for this, according to

Borsay, are that social scientists in the later nineteenth century, while aware of the value of social history did not attach the same value to the history of disability. In part, this may be due to the delay acknowledging social history, as an area worthy of prolonged study. It is only recently that issues of disability gained entry into academic discourse, because disability concerns were regarded as a medically regulated phenomenon, rather than a socially constructed form of oppression (Borsay, p. 101). Thus within the academeia discourses involving disability oppression were not acknowledged as a topic for study (Oliver, 1990). It is difficult to work in an area whereby few, if any, templates of understanding the impaired body or mind have been developed (Garland-Thomson, 2002; Wendell, 1997). Garland-Thomson writes, "there has been no archive, no template for understanding disability as a category of analysis and knowledge, as a cultural trope, and a historical community" (p. 2). The reason for this void is not that disability is a new concept to the culture, but rather that we have consciously chosen to ignore its previous existence. She suggests that scholars have falsely believed the topic of disability oppression is narrow and therefore removed from mainstream thought. While a feminist perspective determines the subject for discussion, it is essential that further insight is gained by adding the lens of disability feminism.

Disability feminism studies issues about the body and/or the mind that is socially labeled as different due to the prevalence of stigmatizing social/cultural normatives, the social stigma of difference, and rejection of difference. Hughes (2005) writes, "with the advent of the distinction between normal and the pathological, it becomes possible to 'see' impairment and to 'say' disability; in addition, disability becomes discursively constituted as a physical or mental deficit" (p. 82-83). What Hughes is saying here is that the social label of disability is about difference. However, the discourses that determine this difference are regulated not by those with disabilities but by authorities, such as the medical authority, who act as the "rational repository of the truth" (p. 83).

Rosemarie Garland Thomson (2005, 2002, 1996) and Susan Wendell (1997, 1996, 1993) have also contributed to the discussion about representation of the impaired body and/or mind. Their theoretical work permits me to specifically question the institutional structures that have facilitated the identification of women with disabilities through disease or illness. However, there are many forms of social labeling and oppression granted to women with disabilities, and others, that have yet to be identified. So embedded are these social structures, that it is difficult for us to see the dominant discourse because we are immersed in it (Harding & Norberg, 2005; Harding, 2004; Lather, 2001).

Including diversity, particularly those historically silenced within society, produces the question of who has the authority to project marginalized voices, and of how can these voices be projected accurately. It seems the oppressed can speak for themselves when provided the venue. The difficulty lies in the indiscernible moments between the processes of speaking and the processes of articulating voice. Lather writes that this gap in time is riddled with inescapable power imbalances (2001). This lapse in time is when voices are heard or ignored; when concepts are understood, discarded, or misinterpreted; and when meanings are formed. The challenge is not to displace or alter previously ignored voices, but rather to accept that it is a fastidious task to accurately reflect marginalized voice. Projecting accurate voice is difficult, as it is acknowledging the complicated process of knowledge production and how differences of location alter perspectives. Coming from a post structuralist perspective, I am not convinced that it is even possible to project the silenced voice through research without altering or dislocating what is being said.

Gavey (1989) describes feminist post structuralism as a way of thinking in which "the goals of scholarship include developing an understanding or theories that are historically, socially, and culturally specific and that is explicitly related to changing oppressive gender relations. Rather than 'discovering truths' reality, 'revealing' truth, or 'uncovering' the facts, feminist post structuralism would, instead, be concerned with disrupting and displacing dominant (oppressive) knowledges" (p. 463). Closely associated with the post structuralist perspective of knowledge production is the means through which power is constructed and perpetuated within the social, economic and cultural segments of society (Weedon, 1987). Locating the historically silent voices of the marginalized through diminishing dominant voice, and thus the voice of authority, is a fundamental principle of disability feminist theory (Reid, 2000; Krogh, 1998).

Feminist methodology seeks to reveal the impact of dominant discourse as a means to make space for previously silent voices thereby leading the way for social change (Reinharz, 1992). Joan Meister (2003) questions how can one think it is liberating to formally acknowledge the misery some women with disabilities endure when there are few, if any, resources to change their circumstances. Meister was not necessarily suggesting that we should not ask important questions, but rather, what is the value becoming fully aware of a situation when there is little social means to support change; words, which haunted me throughout the latter half of my research.

As the final stages of editing began, I came to think that making space for previously silent voices did little to transform the realities in which women lived. Thus, I have to wonder if the goal of ensuing social change signifies a gap between the desired outcome of feminist methodology and the realities of what it is actually like to work with marginalized women. Marginalized women may desire to have their concerns heard, but I wonder how enlightening is it to keep repeating the message year after year. The realities of women with disabilities are that many live in poverty, discomfort, remain unemployed or underemployed, or hold little status within western society. It is also an overwhelming task to feel that one must lead a group into social change. This speaks not only to the complexities of some feminist research methods, but to the need to examine how realistic our expectations have become when research involves marginalized people, such as women with disabilities.

Throughout my research there was friction between accepted ways of doing within the university and accepted ways of doing within the Centre. It is not that either way was correct, but rather different. *Whose* logic was being acknowledged as the authority was a question I asked myself frequently. Developing the means to challenge established authority is another fundamental value of feminist examination (Gavey, 1989). Butterwick & Dawson (2005) suggest that today's academic practice stems from the patriarchal framework of logic, rather than from what has been dubbed the feminist framework of emotion. Logic has evolved, and is presently presumed to be a more advanced process of knowledge production than emotion. More discussion about the power of logic follows in Chapter 3.

The consequence of a logic-based approach is that if a particular way of doing does not feel to be the best way to go, the approach may still be justified by logic or reasoning. For example, within Chapter 1, I stated I felt uncomfortable re-working the data from the PAR for personal academic gain. Logic can diminish this emotional response, because I have the consent of the participants to do such work. Diminishing or outlawing the value of emotions may contribute to the sustenance of traditional academic practices or ways of doing (Butterwick and Dawson, 2005). Yet, identifying the difference between logic and emotion may not be as simple. Feminist methodology encourages research approaches that examine competing constituencies and power relations. But examination of issues that will be presented in Chapters 5 and 6 of this thesis suggests to me that, while one may take a feminist approach, integrating the histories associated with oppression necessitates a shift in the overall feminist conceptual framework. While disability feminist academics, such as Garland-Thompson (2002), support a merging of concepts, such integration requires a deconstruction of years of logical thinking. It is the task of feminist disability scholars to address some of the widespread misunderstandings related to disability oppression through deconstruction of ideologies, resistance to dominant discourse, and reimagining new ways of doing (Garland Thomson, 2005; Wendell, 1997). We can integrate less known disability theorizing with the works of the larger and more dominant feminist thought. Harding and Norberg (2005) write that dominant groups are less able to see their own oppressive tendencies, beliefs, and practices, because the tools for doing so do not necessarily exist. Indeed, Harding and Norberg write that "androcentrism, eurocentrism, racism, heterosexism, and bourgeois values have generally been shared by research communities. Consequently, these cultural values and interests have tended to persist unnoticed in the social sciences until pointed out by social justice activists" (2005, footnotes, p. 2010). Even within this 'list' provided by Harding and Norberg, there are omissions such as ablist ideals and the western tendency to believe dominant Christian beliefs are superior to the beliefs of other religious practices. I am sure that there are more words to reflect the narrowness of our values. This is one of the shortfalls of lists; while serving to include, they will likely exclude as well.

Academic disability feminists challenge white western feminists to remember that their methodology should produce new ways of doing through processes that do not mimic traditional patriarchal tendencies. However, there is a debate about whether this approach is achievable (Harding & Norberg, 2005). Others suggest that reflection back on the research process may highlight some pattern of domination (Oakley, 2000; Schratz and Walker , 1995).

Fonow and Cook (2005) describe feminist methodology, as a methodology that is ever changing, reflecting back onto itself , and evolving to become more inclusive, accurate, and further away from the dominant discourse, and the master's tools (Lorde, 1984). Feminist methodology resists the traditional fixed position and concentrates on creating fluidness or plurality within research. Traditional science suggests that there is a right way of producing knowledge whereas feminist perspectives acknowledge many forms of discourse produce knowledge: none more nor less valid than any other (Gavey, 1989). While arduous at times to conceptualize, there is great value in resisting the fixed position.

Reflection back into the process provides potential for more effective research methods. Critical analysis, seeking the overlooked or presumed innocent of the past, deconstructs presumptions of dominant discourse. Thus, feminist academics become conscious of the error in the presumption of one way of doing (Gavey, 1989). Reflexivity, in regards to feminist methodologies, promotes unremitting drive for change, and greater inclusivitity of all women and other marginalized groups.

Making a space for previously silent voice really means another traditionally dominant voice must be dislocated or at the very least, become less powerful. Identifying and redistributing power or the energies that sustain power is a fundamental element of critical discourse analysis. Foucault (1980, 1972, & 1965) has written a great deal about discourse and power. Dorothy Smith (2005) writes that she interprets some of Foucault's work, as reflecting a means to disconnect traditional ways of thinking so to reconfigure our understanding of power and authority. Upon examination of the various methods of analysis it appeared to me that critical discourse analysis was one way to answer my questions relating to the dynamics of power.

2.2 Critical Discourse Analysis

It was a highlight of my academic and community life to take part in the PAR project. My feelings of intense enjoyment conflicted with the discomfort that came as a result of some power issues which arose during the project. Some of this conflict I thought was predictable, and some was unpredictable, and as a result this thesis has become a venue to examine why some of this conflict happened. The value is that this developes formal thought about whether the conflict was localized to this one project, or was a larger example of how power plays out within partnership.

Critical discourse analysis is a set of methods used by a wide spectrum of academics, from a variety of disciplines (Rogers, Malancharuvil-Berkes, Mosley, Hui, & Joseph, 2005; Sutherland, 2004; McGregor, 2003; Henry & Tator, 2002; Johnstone, 2002; Chouliaraki & Fairclough, 1999; Mills, 1997; Dellinger,1995; van Dijk, 1993; Kaplan, 1990). Rogers, Malancharuvil-Berkes, Mosley, Hui, and Joseph (2005) write that critical discourse analysis is “a cultural tool [that] mediates relationships of power and privilege in social interactions, institutions, and bodies of knowledge” (p. 367). Insight into this process of mediation happens when one asks who benefits, and who does not benefit, from the way something is written or presented (McGregor, 2003). The problem with this is that it is difficult at times to acknowledge and deconstruct dominant ideologies as to who benefits. Demystifying claims set down by dominant groups, media, and the elite, and providing the perspectives of more marginalized groups is quite challenging. It can be difficult to comprehend the full scope of an issue if one has no point of reference. The deconstruction of dominant ideals must envelope a social and historical perspective that contributes to the understanding of past power relations between dominant and subordinate groups (McGregor, 2003; Henry& Tator, 2002). Opportunity to understand in part, the consequences of oppression, dominance, and inequity within a research environment designed to equalize the balance of power attracted me to feminist critical discourse analysis, as a tool appropriate for this case study.

Feminist critical discourse analysis breaks down variables such as differing values, perceptions and histories, which enables an increased contextualization of interpretations, as well as how these interpretations consider or ignore power and authority (Fonow & Cook, 2005). Feminist critical discourse analysis, for the purposes of this thesis, focuses on the context in which we communicate, while acknowledging the political influences of language. From this standpoint the analysis begins with the understanding that our language systems cannot be presumed neutral (Rogers, et al 2005; Chouliaraki & Fairclough, 1999).

Using feminist critical discourse analysis as a means to mediate power and privilege, this case study extracts specific passages from a variety of data sources as discussed in the following data section. Data is then examined in relation to who benefits, who does not benefit, and why this may be so. Much of the focus of this work relates to the role of the university when involved in a community research partnership. This approach was deliberately chosen because traditionally I think the university is seen as the institution that has historically been responsible for research. As well, the university has an ethical review process that support setting the standards for research practices.

Fundamentally, one goal is to look beyond the set of socially imposed beliefs and traditional language practices for exclusionary practices and structures (Mills, 1997). Because this case study is in retrospect, it will alter nothing in the original research project. However, the highlighted discussion around selected points within the research project offers the opportunity to rethink the complexity of working beyond dominant discourse. These highlighted points are situated within political influences, history, culture, and social interaction.

My desire is to broaden the conversation and my concern is that such a conversation be interpreted as recreating what Rogers et al (2005) would call its own regime of truth (p. 368). To avoid this misconception, the analysis is placed within the context of a case study. Working within a case study sets a boundary which states, that while some issues might be generalized within other pieces of literature, the conversation is limited in scope to the examination of one project.

2.3 The Case Study: Benefits and Limitations

Revisiting the question of what works and what does not work makes this case study a practical examination. While some information may reiterate findings in other research it is very much about one specific case. While not creating a quantifiable type of analysis, this approach does offer the potential to practically reflect back on how a specific methodological process worked within the confines of one group of marginalized women.

A feminist case study offers a venue through which there can be examination of social phenomena via an individual case, rather than as a comparative analysis (Reinharz, 1992; Padula & Miller, 1999). Robert Stake (1998) writes about a case study, also referred to as reflecting fieldwork, as being, " ... not the methodological choice, but a choice of object to be studied" (p. 86). The case study is one approach among many others that necessitates in-depth study (Stark& Torrance, 2005). Stark& Torrance write that, "case study assumes that 'social reality' is created through social interaction, albeit situated in particular contexts and histories, and seeks to identify and describe before trying to analyze and theorize" (p. 33). This process is the purpose of this thesis. Therefore, the case study has the potential to offer more than it might initially appear as the contribution of the framework of history and social discourse links to the synthesis of the data (Stake, 1998). This allows the researcher enhanced understanding of all groups involved in the research (Rothe, 1993).

It is an asset that case study is a lone piece of work or even a portion of the work explored by multiple methods (Stark & Torrance, 2005). Intensive scrutinizing facilitates understanding of the data from which the findings may stand alone or be compared to other cases. Stark and Torrance describe the case study as a method "illuminates the readers' understanding of an issue" (p. 33). The case study fulfills a supporting role, as it makes possible one understanding of a process and its potential impact on the collaborators.

Conversely, the weakness of a case study is that the findings may not correspond to other information collected. Limited to one study unexpected study findings cannot be generalized into a new trend. As a case study, this thesis reflects findings within one purposively selected group of marginalized women. Who reads this, whether it is limited to academics, or to those involved in the research, and how my words are interpreted, are factors that will the influence the widespread effect of this work. This reflection has enhanced my understandings of my primary research project and what I take from this case study will influence any future research work I may become involved with. Another venue to share information created from this case study is academic publishing, and community discussion about how the research process may be enhanced to better serve the specific needs of women with disabilities.

On a very different level, the case study provides a venue to bring disability issues into the conversation by using the lens of an individual with a disability. Susan Wendell writes that, "I have to say that having a disability usually gives a person experiences of a world different from that of people without disabilities, ... and that these different experiences create the possibility of different perspectives which have epistemic advantages with respect to certain issues." (1996, p. 73). My struggle to uphold disability feminism within my case study lay in finding words that accurately articulate why some power issues continue to exist when collaboration involves a dominant group and a marginalized group.

However, I know power issues did exist within the research project because, despite the passage of time and my development of academic thought, the data remains what it is, providing the clues that the case study reveals.

2.3.1 Data

Multiple sources of data collection are gathered and presented so that the reader gains insight into the context in which the events took place. Data sources for my primary research included: recordings from four group interview sessions, one personal interview, e-mail that was collected over the space of one year primarily from participants, and various government publications focusing on disability issues. The data for this case study concentrates on much different materials than those used in my primary research. For this case study I used: e-mail, largely between collaborators and several advisors and between collaborators and the university's Office of Research, and other data sources such as personal journal entries, the university research policy as published on the Internet, portions of the ethics submission and a section of the Invitation to Participants of the primary research, a personal letter I sent to the Board of Directors at the Centre, and finally, a letter to me from the Board.

My purposive selection of data removes any sense of researcher innocence, and discloses my own influences on this secondary research, meaning that this work accentuates a process very different from decision making by consensus. He primary research was designed to encourage inclusivity and this case study, in which I am the sole regulator of the content, is a work of one. To start this process, and in an effort to collaborate on key points of interest, I asked my research assistant in the primary research to identify what issues stood out to her throughout the life of the project. Any issue or incident that created conflict is referred to as a point of interest, and together we sat down and made a list of points of interest to work from.

Some time later, when the research question was formulated, I examined each point and reduced the list to a more manageable size. From this revised list I purposively selected six points of interest. When I began an analysis of these six points I realized that this involved very lengthy analysis chapters. Therefore, the six points were further reduced to the four that I felt best answered my research question; how do issues of difference and representation influence the process of participatory action research. The four points of interest include:

1. Participant Selection
2. Negotiating the Rules of Financial Management
3. An academic Request and Community Resistance
4. Varying Interpretations of University Research Policy

There were three reasons why I chose these points of interest. Firstly, to identify and address areas that involved discourses of difference and authority. Secondly, to initiate scholarly reflection through which academia can begin to reimagine other ways of doing, and thirdly, to look at discourse as a silent decoder of messages and acknowledge how dominant discourse structures the world around us.

2.4 What's Next?

The following chapter speaks to the complexity and subtly of difference and representation. It constructs the framework that reveals dominant beliefs and practices about knowledge production, difference, and representation. This examination expands our understanding of how marginalized women, their histories, and their social location may impact the research process.

CHAPTER 3

Constructing the Framework: Difference, and Representation

> Stereotyped assumptions about persons with disabilities are often based on superstition, myths, and beliefs from earlier less enlightened times. They are inherent to our culture and persist partly because they are constantly reproduced through the media.
> - Paul T. Jaeger and Cynthia Ann Bowman, 2005

When my nursing shift in the neonatal intensive care started that Monday morning, the day did not seem much different from any other. Just hours later, I became suddenly ill, and required intensive life-supporting medical intervention. Despite having had no past history of serious illness, suddenly I became aware that my sense of health had evaporated and illness had moved into its space. If I had to identify one life altering experience, I would say it happened on that Monday, because I was no longer the nurse, but rather had become the patient. Although I struggled to believe I was the same person occupying the same, albeit changed body, something intangible had happened. I was no longer in a position of knowing, but rather was deemed in a position of need, and others deemed themselves the experts about my own body. Within the confines of this unwelcome world I felt no sense of control.

This intangible transformation appears contradictory as my sense of self arises from places beyond the evolution of sickness and limbs that may or may not work as expected. If asked to define my being, my response evolves from a spiritual location rather than a physical level. However, once I became ill and subsequently afforded the social label 'disabled,' messages from people around me placed me in a space very different from the one to which I was accustomed. I developed new ways of doing tasks, but others presumed me 'unable' because physical limitations forced me to manage my life differently. I am unable to articulate with accuracy how this experience made me feel, almost automatically, different, but the forces that allocated difference originated outside of me.

This chapter examines some discourses on disability within western society. It demonstrates how representation is closely linked to discourse that distinguishes difference. The quote at the beginning of this chapter by Jaeger and Bowman (2005) addresses the diversity through which difference and representation are constructed. The words symbolize a reminder that constant reproduction of mainstream discourse maintains stereotyped assumptions about persons with disabilities.

3.1 Bio-Energetic Shrinking

My illness involved an intangible transformation that did not resolve over time. In fact, as the effect of illness and medication ravaged my body, and to some extent my mind, I became aware of the progressive social shift away from the center. It seemed to me that all authority, energy and prestige attached to the intensive care nurse position quickly dissipated into a disease entity, that carried little sense of control or power. As chronic illness evolved into disability, I gained a greater understanding of what it is like to be the 'Other' (Wendell, 1996). I use the term 'Other' beyond the context of Simone de Beauvoir's initial description of the 'Other' in terms of woman as inferior and subordinate to man (Tong, 1998). de Beauvoir theorized man's reaction to the threat of woman as a means to subordinate woman to maintain man's freedom. Susan Wendell (1996) writes that 'Othering' is a technique used by some in society who have no concept of what it is like to live with a body and/or mind different from them. Beyond this sense of biological determinism is 'Other' as the subordination by some in society through the use of dominant ideals.

There are a number of expressions used to describe concepts of marginalization such as 'Othering'. For example, Charlton writes, "besides the ubiquitous conditions of poverty and degradation that surround it, we know that when a person becomes disabled, she or he immediately becomes 'less'-what Wilhelm Reich refers to as "bio-energetic shrinking"(1998, p. 7). Bio-energetic shrinking speaks to the very transformation I described at the beginning of this chapter when at one moment in time, one was no less healthy from the moment before, and the next moment when sickness entered and illness dominated. The lines of difference that are attached to physical, and even more so to mental impairment, as defined by modern western social standards, are subtle which makes them difficult to identify. Comprehending the intricate reality of masked discourse is most effectively revealed through the voices of those have the lived with oppression.

Recordings of oppression may be found in the text of ancient histories (Edwards, 1997; Jaeger & Bowman, 2005; Rosen, 1968). Indeed, reports of mental and/or physical impairment have been spoken of in literature in ancient Greek writings (Edwards, 1997) as well as the Bible (Rosen, 1968). As described in chapter 2, the ways we understand discourse are historically, culturally, and socially specific (Gavey, 1989). Therefore, it is impossible to put ancient writings into meaning using today's standards because disability, as culturally constructed in modern times, would have no inherent meaning in the context of the ancient past. The problem with understanding the lived experience, within the unspoken confines of post structuralism, is that the notion of creating an authentic voice appears unachievable because such meanings are interpretations of language which is inherently socially constructed. In other words, by describing the lived experience one is utilizing the tools of modern language, which constructed the difference to begin with. However, as a person who has lived both with, and without, a disability, acknowledging the limitations of producing knowledge within the restricted boundaries of how language is constructed and understood, it remains pivotal that one does attempt to articulate these inherent boundaries of difference. Thus, disability feminism strives to not only articulate difference but to deconstruct the forces that build and sustain the dominant discourse which discriminates because of difference (Garland-Thomson, 2002).

Anita Silvers (1994) claims it is unlikely that those without disability can even begin to imagine the discrimination afforded those who live a life with a disability. Susan Wendell (1996) writes that living with a body or mind impairment provides experiences beyond the understanding of those living without such impairment. I agree with both Silvers and Wendell. To begin the process of articulating the oppression of disability, the conversation begins at a point before theorization and analysis. It begins with an examination of some of the forces that influence our thoughts concerning the impaired body and mind.

There is a risk that pieces of this conversation may be difficult or rejected, because such study may challenge our personal knowledge and beliefs. A writer, teacher, and Black activist, bell hook describes how difficult she has found it to express her point of view when such a view is not commonly supported in society. She writes that, "these [critical essays] represent my political struggle to push against the boundaries of an image, to find words to express what I see, especially when I am looking in ways that move against the grain, when I am seeing things that most folks want to simply believe are not there" (1992, p.4). The benefit of hearing the voice of oppressed people is that it is another venue to share knowledge.

3.2 Holding on to Beliefs

Directly linked to knowledge production are power and control. Thoughtful and informed choices can influence knowledge and advance change. However, both knowledge and change depend on who controls the power, and their desire to relinquish power (Gatenby & Humphries, 2000). Thus, knowledge production, ways of knowing, and changes are entrenched within paradigms of power.

Feminist theory identifies the need for knowledge as powerful because the goals of feminist ideals challenge and change the patriarchal world (Nash, 1994). A post structuralist feminist lens theorizes that knowledge is not constrained to a fixed state, but the feminist role of trying to promote change through knowledge production becomes complicated. Nash writes that, "knowledge consists in having, at best, good reasons for holding the beliefs one holds about the world and, at least, no-good reason for giving them up" (p. 72). Claiming that this way of thinking prevents one from seeing knowledge as a positivist truth, yet it is possible to hold onto beliefs for good reasons and to be motivated to act because of such beliefs. A disability feminist lens demands that we examine these beliefs or 'ways of knowing' for embedded dominant discourse that discriminates against marginalized people.

Lather (1988) articulates three fundamental feminist assumptions that influence our ways of knowing:

1. Feminist assumption rejects the notion that all knowledge can be understood within a positivist approach.
2. The way one looks at the world is inherently bound to socio-cultural influences and lived experiences.
3. The purpose of feminist research is to empower the researched and contribute to the generation of change orientated social research.

In Chapter 2, I discussed the feminism rejection of the one 'true' way of doing, the key methodological of the positivist approach. A positivist perspective occurs when an individual believes there is one right way to think about or to solve a problem (Stanley & Wise, 1993). Positivism is "a single reality [that] exists independently from the inquirer's interests, operating according to a set of laws that take a cause-effect form" (Israel, Schulz, Parker, & Becker, 1998). Resisting the positivist approach to knowledge becomes a constructive acquisition, and opens the mind to other ways of knowing.

PAR operates from the premises that there are many experiences that have not been accurately reflected or have been misunderstood by mainstream society. One basic tenant of PAR is to shed the notion that there is one way of making space for the voices of people, who have traditionally been silenced. However, as Silvers (1994) states it is exceedingly difficult to comprehend the experiences of others, without having had similar experiences ourselves. The process of understanding the experiences of others is inherently bound to socio-cultural influences of our own lived experiences (Lather, 1988). Our ability to decipher various influences and perspectives is pivotal in understanding the deep-rooted relationship between knowledge production and legitimacy (p. 570). Feminist education reveals trends within deep rooted and pervasive influences that have become intricately inherent structures in our society. Thus, the authentication of the lived experiences, such as disability oppression, is limited by the ways in which we understand and created meaning from language.

Knowledge, produced as a result of feminist research serves to "empower the researched and contribute to the generation of change enhancing social research" (Lather, 1988, p. 570). Lather calls for feminist research methods that do not replicate traditional research but rather offer a diversity of practice. This diversity demands an expansion of understanding and acknowledgment that, traditionally, knowledge is produced from the dominant discourse. Chapter 2, identified the importance of diversity through the inclusion of the voices of traditionally marginalized women, such as women with disabilities, into feminist conversations. In chapter 2, claims were made that the disability perspective has been absent from feminist theory . It does not, however, appear to be enough to inform mainstream society of oppression due to bodily/mind differences. because providing this information has not resolved the poverty, the unemployment, or the violence.

The following three sections expand upon the impact of feminist attempts to move beyond the historically patriarchal means to knowledge production to become inclusive of other ways of knowing. The following section describes how a society knows what it thinks it knows through the concepts of gatekeeping (Lewin, 1958), and knowledge production, oppression, and resistance as described by Paulo Freire (1970). The second section describes the need to evoke change as means to repudiate the patriarchal world in which we live and how this change may evolve (Reinharz, 1992). The final section speaks to how defining authoritative lines of normatives, results in the formation of boundaries that includes some, and excludes others.

3.2.1 Gatekeeping and Resistance to Change

To formulate an analogy that describes the resistance to new knowledge as well as societal control over knowledge production Lewin used the term's *gatekeepers* and *gatekeeping* (1958). He used the word *gate* to illustrate the notion of a door that depending upon which side receives a force to move the object has the potential to swing open. The *gate* is a process that offers the potential to support and/or halt change. In one sense, the gate can raise awareness so that the desired change is greater on one side and then the potential to change behavior will follow. On the other hand, the gate can decrease the resistance of the opposing forces, again creating an imbalance in power bringing about change. Lack of movement suggests a status quo with no desire or tools available to resist or open the door. The *gatekeepers* are the individuals, group of individuals, or social structure that attempts to regulate the opening and closing of the gate and thereby manipulate change. In regards to evoking change, Lewin that states it is important not only to anticipate the role of gates and gatekeepers, but also to look at the social context in which specific behaviors are taking place.

The Independent Living philosophy often examines issues of power through the concepts of gate keeping. Kari Krogh (1998) writes that even within partnerships designed to negate inequalities of power there is exploitation by dominant partners. She writes that people, well versed in the Independent Living philosophy, may become frustrated by such an approach. I experienced this type of reaction when discussion began about who should control my research funds (Chapter 5). When I looked into university policy about how research funds are distributed through their system I found issues that I felt did not fully respect the interests of my participant. My interpretation of this management system is that it comes attached to a long line of rules and regulations. While described in detail in chapter 5, it was my experience that the inflexible rules and regulations for the control of funds are an example of institutional gatekeeping.

I approached an individual at the university about the university research policies such as, the way the research funds are paid to participants. My particular concern was that it was deemed mandatory for participants to provide social insurance numbers, which would be kept on file for seven years at the university, in order to receive an honorarium for their participation. I was informed that such rules are flexible, but that the interpretations of the words are often firmly anchored. Placing blame for inflexible policies makes change difficult, because the problem is put onto the individuals interpreting the policy rather than onto the policy itself. Therefore, clarifying the policy is not possible because the policy is not deemed to be the problem.

Challenging the means of knowledge production is not a simple task, because knowledge has historically been under the control of those who hold power (Chaudhary, 1997). One example of this is society's division between the rulers, those with knowledge, and the ruled, those waiting to receive the knowledge. The predominant control of knowledge in many cultures emerges from a top down patriarchal hierarchy, in that those at the top determine what it is those on the bottom need to know. Thus, both the learning process and knowledge production have become methods whereby the authoritarians or custodians of knowledge develop positions for themselves and a small select group of other key individuals, to control the power derived from knowledge (Chaudhary, 1997). Little emphasis is placed on the knowledge generated by those whose lives are located at the bottom of the hierarchy. Thus, another challenge for research involving marginalized people is that those on the bottom, who wish to be heard, must displace those on the top who traditionally control the flow of knowledge.

Reconfiguring the learning process resists traditional means of knowledge production and defies the top down pyramid approach to knowledge production. Paulo Freire, a Brazilian educator, (1970) renowned for his writings on knowledge production and resistance to change, worked within oppressed populations. Freire describes the traditional system of learning as a banking approach, in which information is "banked" onto the student. Under this system of learning, the role of the teacher is, "to fill" the students with specific information. Traditional positivist approaches to learning reinforce ideals that there is one right way to learn, to solve a problem or to find new answers. These positivist approaches conflict with feminist approaches to learning that encourage diversity of thought, and acknowledge differences of perspective (Lather, 1988). Avoiding traditional knowledge production entails a rejection of the banking approach (Sharma, 2001; Allman & Willis, 1997; Freire, 1970). Such a rejection requires a major shift in teaching and producing knowledge as Freire's promotion of self discovery within the adult encourages the educator to shed the notion that she has and knows all of the answers (Sharma, 2001). Acquisition of knowledge becomes an "act of cognition, [rather than a] transfer of information" (Freire, 1970, p. 67). Education is a means of knowledge production, similarly research is also a means to produce knowledge that promotes change. Within the context of PAR some stakeholders, immersed in traditional ways of learning, may find it difficult to follow or may resist traditional the ways of producing knowledge.

Change potentially reconstructs society's understandings of itself. One way to achieve a new understanding is to conceptualize the influences of discourses that establishes difference. This conceptualization of difference is the subject of the following section.

3.2.2 Influences that Construct Discourse of Difference

Discourse speaks to the ways in which cultures, societies, groups, or historical periods construct meaning, which is not static, but rather ever changing. This section identifies some of the influences that construct discourse of difference.

The problem of embedded dominant discourse is not new to feminist thought and consequently to feminist research methodology. Feminists have difficulty unveiling dominant discourse because it was rooted thoroughly and at times subtly embedded into all features of western society. The pervasiveness of discourse makes change difficult. Edwards and Ribbens (1998) discuss the problems of research in non-Western countries by western researchers, who tend to clutch tightly the white, middle class, ableist, heterosexual, male discourse. They state that, "researchers in these areas cannot escape the requirement to take cultures and discourses that are peripheral to predominant Western knowledge forms and 'translate' them into a discourse recognizable to public audiences" (p. 3). Thus the voices of non western women have had a tendency to be filtered through the lenses of the privileged and predominant western way of knowing, again reinforcing western discourse and strengthening the 'Other' effect. The dominant forces behind white western discourse infiltrate what we know, becoming the yardstick through which we measure and create the Other.

The perspectives of white middle and upper class women have dominated traditional feminist discourse and theory (Hill Collins, 1999; hooks, 1990). Black feminists have been vocal about the dichotomy of white feminists speaking of, and for, the *sisterhood*, and the value of the shared experience, even though black women were entering their homes as cheap labourers, cleaning their floors and bathrooms. Supported by criticism of the treatment of Black women and claims that feminism originates from a white perspective, Black academics have challenged the concept of the homogeneity of the authority of feminism. As a result, Black feminist women have distinguished themselves outside the general term of feminists and more specifically as Black Feminists. Black feminist and others, such as disability feminists, contribute to post modern feminism. Part of the reason for this separation by difference in the post modern academic world lies in the difficulty of researching the discourse of difference and arranging it in a piece of literature that is relational to academics outside of such discourse (Edwards and Ribbens, 1998).

However, exclusion is not a practice that affects only Black women. 'Woman' represents widespread diversity and, within this diversity, are women who experience various forms of marginalization. For example, the white middle class representation dominating the second wave feminist movement offered little to women marginalized by factors beyond gender such as race, ability, religion, sexual orientation, and so on (Lal 1999; Ferri & Gregg, 1998). Grahame (1998) describes a job she had as researcher for a white feminist organization to determine why women of color did not participate in the women's movement. Grahame concluded that it was not that women of color were absent from the general women's movement, but rather, that women of color were not particularly interested in the way white women participated in the movement, because Black women had different ways of doing so. This is one demonstration of how the dominant feminist discourse may misinterpret the actions of women who experience the intersectionality oppression of gender and race.

Within my research, I experienced a pervasive attitude similar to those articulated by Grahame (1998). Some of the language used within the university ethics policy was particularly disturbing to myself and the community co-investigator. University determination of what constitutes a vulnerable person clashed philosophically with both the Independent Living point of view, and with the point of view expressed by many disability activists. My inability to adequately articulate this concern to evoke change speaks to my status within the university and the hierarchal power structure thereof.

Power is strongest at the centre, and similarly dominant discourse, as it exists within the every day, enables labels and discriminatory practices, both apparent and unapparent. As a result some people, such as women with disabilities are displaced away from the centre of power and into the outfield. The further from that centre one is, the less power one has and therefore the less desirable one is. Those who reproduce the discourse are generally associated with the centre because this is the centre point from which knowledge is distributed. Further away from this powerful centre where discourse is constructed are the marginalized.

Making space for the traditionally silenced voice, the marginalized, suggests those in the centre are willing to bring forward voices from the periphery. However, despite good intentions, what is said by those located on the margins of society is interpreted by dominant discourse. The following section examines who reiterates discourses of difference for women with disabilities through representation.

3. 3 Representation

The word representation is one of the domains on which feminist theory is constructed (Garland-Thomson, 2005). Garland-Thomson states that widening ones' perception of what it is that constitutes representation augments our understanding of not only feminism, but concepts of difference. Sorrell refers to representation as "the body of shared understandings that constitute the medium through which individuals engage in transactions with one another, with the world they share, and themselves" (2004, p. 159). When applied to disability issues, shared understandings may be desired or undesired and characteristically not in the control of those being represented.

3.3.1 Representation: The Lateral Connections of Cognitive Authority

Examining the well-quoted text *Truth and Power*, Foucault illustrates the "lateral connections" between various forms of knowledge production (1972, p. 126). The value of such illustration is that it enables an understanding of the interconnectedness of knowledge production, experts, and authority within society. For example, how the concept of disability is and has been represented in Western Culture lies within an accepted cognitive authority. "Cognitive authority … means the authority to have one's description of the world taken seriously, believed, or accepted generally as the truth" (Wendell, 1996, p. 117). Cognitive authority enables those who hold the power to make determinations about others. Traditionally, in regards to women with disabilities, cognitive authority is not within the domain of the woman with the lived experience. Frequently, the people who supply information about disability issues are not those who will have to deal with its implications (Thomas, 1999; Wendell, 1996). Thus, the 'expert' becomes someone who may never have lived with the form of oppression.

All too often disability is portrayed as a 'misfortune' or 'tragedy' (Thomas, 1999). Carol Thomas writes that mainstream society believes women and men with disabilities are viewed as "…dependent, limited, and objects of pity" (p.17). Thus the measuring stick for determining normative values is held by those with privilege, and not the marginalized or different. As a result, on both an individual level and systemically throughout western society, impairment or disability has become a marker of difference. Earlier in this chapter, I discussed an indiscernible moment in time when, due to illness, I crossed some imaginary line and became a part of the 'Other', though clearly not through a process of self-determination. Neither, is the marker of difference gender free. Garland-Thomson writes that illness, like poverty, has become femininized or gendered feminine (2005, p. 10). This gendering of illness has significant impact on the overall view of disability, reproduction, and sterilization (often forced).

Designating the social status of difference of the body and/or mind is a determination traditionally granted to medical authorities. One of the problems with this perspective is the diffuse power granted to medical experts not only in diagnosing and managing disability related issues, but also that this cognitive authority extends well beyond the patient-physician relationship as it seeps into general society. Susan Wendell states, "… authority operates far beyond medical institutions – inside and in relation to government bureaucracies, insurance companies, courts, schools, charities, rehabilitative organizations, and institutions for long-term care" (1996, p. 117). Thus, the pervasive medical authority extends beyond the physician's office and influences our everyday lives. The social authority of *knowing* permits medical experts to determine the boundaries, rather than those who live with physical and/or mental impairment.

Lateral connections, as described by Foucault (1972), are pervasive throughout society. The federal and provincial levels of government within Canada operate disability support programs through systems of classifications. For example, individuals with disabilities have support systems regulated by the way governments perceive their physical and/or mental deficit. The problem with this approach is that disability issues do not adequately focus on how to incorporate the individual within mainstream society. Rather, these classification systems attempt to place people with differing needs into rigid and unaccommodating social support system. For example, an individual might be financially supported to obtain a wheelchair. However, the necessity for all buildings to be wheelchair accessible is not supported within present social programs. Therefore, disability support programs are not portrayed as a means of producing an inclusive society, but rather are configured as systems of reliance and government pay out. I suggest that living within the confines of these social programs influences one's perception of classification systems. A specific example of a reaction to classification systems is discussed further in chapter 5.

3.3.2 Representation: Through Contemporary Interpretation of History

To understand how issues of difference and representation influence the process of participatory action research one can look back in time in an effort to disclose that disability is a socially constructed phenomenon. Foucault (1965) speaks to the manufactured manner in which mental health and institutionalization evolved following the demise of leprosy. Mental illness was constructed, or at least envisioned as in need of institutionalization, because of the needs of the greater society. "Confinement was required by something quite different from any concern with curing the sick. What made it necessary was an imperative of labour" (Foucault, 1965, p. 44). Manipulation of national employment problems enabled those who controlled the power to shift the burden away from themselves as government leaders and onto individuals. The result was that these manmade imperatives contributed to defining lines of normalcy, stigmatizing those with differing bodies and minds, visualizing some in society as in need of fixing.

Hence society's *need to care for* madmen was a constructed situation, that served the greater good of society to avoid large scale unemployment and subsequent social unrest. A consequence of this social response was that people in authority decided the fate of others. This is one example of the prolonged history of others speaking and deciding *for* people with disabilities.

Not everyone is open to Foucault's interpretation of history, Fairclough (1992), for example claims Foucault's perspective of discursive practice illustrates the rules of the formation of objects, whereby objects of discourse are created in relation to societal rules and practices. In the conversation about mental illness, the discursive practices become not a stable quality but rather one that 'becomes' through the transformation of words, descriptions, explanations, and names. Edwards and Ribbens (1998) declare that Foucault's perspective sometimes falls short for them as well, stating that Foucault's depiction of discourse development concentrates only on the formation of public discourses and that within the public there are deeper, and hidden constructions of power. Foucault's male and classic construction of knowledge, according to Edwards and Ribbens is located within the sphere of dominant public discourses, as constructed by political movements. They ask if Foucault does not represent the colonizing view disguised by academic rhetoric.

I include Foucault' s position because, as I understand it, I believe there is merit in his position. From a practical point of view, when devising participatory research with groups, who have never had a voice within society, one must be very aware of their history. One can predict a resistence to relinquish any voice that has been reclaimed, a point which became apparent throughout my research. Chapter 5, describes the reaction of the community Board when the academic co-investigator suggested that I resign my position from the Board. The community resisted this advice because of their perception that someone was deciding *for* them what needed to happen for their interests to be protected. The issue went beyond good research practices and focused on reclaiming voice, an in depth discussion of this issue follows in Chapter 5.

There are others beside Foucault who describe historic evolutions that take the disabled body and mind from the perceived normal, and into a new category of the perceived abnormal (Garland-Thomson, 1996; Bogdan, 1996). Social construction of the *abnormal* body as illustrated by Robert Bogdan (1996), describes the impact of the western 'freak shows' as related to disability and body form. Bogdan suggests that the Freak shows began around 1840, peaked, and then fell in popularity around 1940. That is not to suggest that the history of the social construction of disability takes place only within the last two centuries but, this is the latest and maybe most influential example because this period of Freak Shows is closest in our memory. Show operators determined appropriateness of freak show participants, and the bottom line was fiscal in nature. "In the hands of professional organizations, the images created will be designed to reach the organization's aim most effectively" (Bogdan, 1996, p. 35). I interpret Bogdan to mean that once the individual's fate is in the hands of a group, than the driving forces of the group will determine the outcome of the individual. Such driving forces served to isolate disabled bodies/minds from within the normative of society, placed them into the social construction of abnormal and therefore in need of scientific repair.

While the venue may have changed, the public need to examine impaired bodies and/or minds remains intact. For example, television talk shows such as 'Oprah', occasionally invite people with significant impairment onto the show to publicly expose their body/mind deficits. Before and after pictures are flashed across the screen and medical doctors describe in detail the miracles preformed as they repaired the so called deficit. This public need to look at bodies of difference underpins the stigmatization of disability. Understanding the concept of stigmas is essential to gaining a consciousness of some power issues that arise within disability studies.

Erving Goffman, (1963) states the word stigma evolved as a result of the individual possessing qualities or attributes different from others. Goffman identifies other classifications of the word stigma as "failing," "shortcoming," or "handicap" (1963, p. 3). He reiterates dominant discourse when he classifies physical deformity as an "abomination or atrocity" which is compared to character traits and criminal behavior such as dishonesty, imprisonment, mental illness, and treacheries he labels as blemishes. There are other definitions of stigmas, for example Neufeldt (1988) describes stigma as a personal attribute which negatively reflects back onto the character or reputation of a group. Boyce writes, “stigma is also a social relationship marked by exclusionary towards general conditions such as poverty or disability” (1998, p. 88).

From a research point of view, it is good information to acknowledge that the social stigmatization of the disabled body/mind, and subsequent hierarchy of social acceptability of various forms of impairment, plays a pivotal part in the ways women with disabilities view themselves. For example, in western society I believe it is more socially acceptable to have a disability that requires a wheelchair than it is to have cognitive impairment or mental illness. An individual researcher, in a quest for diversity, may want participant representation from a broad spectrum of disabilities. However, problems arise when participants are selected based on identified type of disability. Issues of participant selection are discussed at length in Chapter 5.

In summary, this section has described instances in which disability has been constructed to serve a need of society. The relevance of this writing in relation to the research question is to articulate the social attitudes of the past and to link the widespread prevalence of such attitudes to the discourse of disability today. Discourses of disability have modern conceptualizations and reiteration within writings, media, and imagery pertaining to disability. More discussion about this topic takes place in the following section.

3.3.3 Representation through Everyday Words and Symbols

This third and final section discusses the impact of words and symbols on the discourse of disability. This serves to reiterate the feminist claim that the further away one is from the privilege of power, the less likely one is to represent the ideal physical image (race, ethnicity, ability, religion) desired by the white, affluent, able bodied, and male centre. Reinforcers of what constitute the disabled image continue to reside silently and pervasively in western culture. The medical model epitomizes the illusion that disability must be fixed, which enables the concept of the Poster Child.

A poster child is configured when media, either through telethons or some form of an advertising campaign, appeals to the masses by suggesting that a child with a disability has a terrible and tragic life because she lacks the funding to have her body fixed. This maintains the social fascination of focusing on 'the fix' and removes public attention and obligation away from the conditions within which many women with disabilities must survive (Thomas, 1999). In other words, such deflection minimizes problems of employment or unemployment, barriers to transportation and education, social isolation, poverty and so on.

Suggesting people with disabilities have succeeded in eliminating identification by disease would be erroneous. The following paternalistic excerpts are from a popular woman's magazine, *Homemakers Magazine* (Strand, 2004) the type of reading one might find in a doctor's or dentist's office. "A few of them like Matthew, who had Downs syndrome give me huge hugs and tell me how funny I am. And Tony, 26, who has seizure disorder, and Candice, who has Fragile X syndrome seem to sense when I need some picking up"(p. 32). These sentences demonstrate *need* by the person organizing the drama to distance her from the actors, and to reinforce her role of the rescuer, the drama instructor. They, or more specifically them (as opposed to us) are seizure disorders or Fragile X or Downs syndrome rather than enthusiastic young adults taking part in a play. They *are* diseases that provide the drama instructor with affection, hugs, and emotional support which appears from some unexpected source of unnatural intuition. One primary concern with this paternalistic ableist writing is that people in the doctors' office reading this article see the language, and what I call an obsession with disability as an acceptable way to approach, think about, and write about bodies and minds that they believe are different from their own. This type of writing contributes to the formation of the traditional western discourse on disability. This article is not an isolated case, and in Chapter 4 there is an example of researchers writing an article where by participants in the research are identified by disease.

Durable and pervasive forces create discourse of language, though such dominant discourse is void of input from those directly impacted (Thomas, 1999; Wendell 1996; Zola, 1993). One strength of PAR is that it allows space for marginalized people to describe how *they* wished to be identified. Too often others in society make this choice for those who are marginalized. Part of this identification within academia is done with the theoretical attempt to include, which in actuality serves to exclude. One example is use of the word differently-abled. This term is likely meant to disclose that some people live life in different ways, such as ambulation through wheelchair. However, this is not considered to be an appropriate term to place on other forms of oppression, such as differently gendered or differently coloured. Wendell (1996) writes that, this type of language is bestowed upon those with disabilities claiming, "this person is not the norm or paradigm of humanity. If anything it increases the 'Otherness' of people with disabilities, because it reinforces the paradigm of humanity as young, strong, and healthy, with all body parts working 'perfectly' from which this person is different" (p. 79).

How people are represented in text and media is an essential component when research involves traditionally marginalized people. For example, in an effort to clarify a contentious issue, the community co-investigator and I looked at the university ethics policy. What resulted was a distancing of the community co-investigator in regards to sharing the academic perspective. The community co-investigator, well versed in the ways text and imagery can discriminate, perceived words within the university policy that has negatively impact one's right to choice. She interpreted parts of the university definition of 'vulnerable' as discriminatory. Well steeped in dominant discourse about disability issues, she interpreted the university policy as reiterating both stigma and dominant discourse. This is discussed in greater detail in Chapter 6.

This section demonstrated ways in which text and imagery represent women with disabilities within modern, western, society. Discussed were some images that accentuate difference, such as the poster child who needs money donated by strangers so that she can be fixed, magazine articles that distinguish actors through physical and mental impairment rather than accomplishment, and some language practices. These varied types of largely unwanted representation demonstrate the marginal impact of voices of disabled people in our society. Thus, the value of highlighting dominant discourse is to demonstrate practices which have become so mainstream that they are no longer detectable by any except those who wish to shed stereotyping of dominant discourse in an effort to promote equity and celebrate diversity. Anticipating these discriminating practices is essential within participatory approaches that include participants on the receiving end of the impact of such discourse.

3.4 Summary

This thesis strives to challenge conventional representations of society beyond what we already believe we know. Via a case study, my purpose is to articulate what we believe we know about disability and to challenge various thoughts with the hope of producing contemplative consideration of the concept of disability, in relation to research methodology, as it is understood in western society today. This study will enhance understanding of how issues of difference and representation are dominant influences when research which includes women with disabilities.

One goal of disability feminism is to explore political concerns expressed by women with disabilities (Garland-Thomson, 2005). Situating the disability experience within rights and exclusions, retrieving lost voice, and challenging mainstream verbal and non verbal means of communication in regards to bodies with disabilities are significant tasks. An essential part of “reimagining” is to expose both the history that has contributed to discourses of disability, and the influences of power and difference that exist in the social structures that maintain these differences. Examination of representation of the impaired body and mind through social authority of the past and present offers the potential to read the script with renewed understanding.

Chapter 4, illustrates the theoretical construction, and some practical applications of PAR. In this chapter one can find a historical and present day conceptualization of PAR, its strengths and its limitations.

CHAPTER 4

Participatory Action Research (PAR)

We are the subject of books and papers
Our lives recorded by the middle class
Who steal our stories, use our oppression
To serve their needs; they won't let us pass.
(Cathleen O'Neill in Class Attack, 1990)

One of the goals of participatory action research (PAR) is to create an environment in which participants do not feel exploited as described by Cathleen O'Neill (Class Attack, 1990). When participants are included throughout the research process, theoretically this decreases hierarchal relations of power that have contributed to exploitation. Researchers often refer to PAR under the umbrella term participatory approaches because it has evolved to include a variety of design methods. This evolutionary process began with Kurt Lewin, who experimented with a non traditional approach to research around the time of World War II (McTaggart, 1997; Adelman, 1997; Cunningham, 1993; Marrow, 1969). He moved action research outside of the laboratory and into the community.

Action research is different from participatory approaches, because it does not consider the role of the participant to be a pivotal piece of the research. The importance of participants within research began to evolve, and action research changed into a form emphasizing the value of the participant. Hall (2005) states, in its earlier stages of development PAR did not consider gender inequity. A second wave of evolution recognized not only the role of participants but developed a focus on gender.

This chapter discusses what PAR is, what it is not, and some of its challenges in relation to its theoretical structure, and finally, its practical applications. There are four principles of PAR for research involving research with individuals with disabilities, which are introduce and presented in detail. The following section provides a description of feminist understandings PAR methods.

4.1 PAR: What is it?

Participatory approaches to research address the divide between the theory and the practice. Rather than approaching knowledge production in a linear fashion it becomes more of an infinite cycle of learning and reflection (Noffke & Somekh, 2005; Wadsworth, 1998). Noffke and Somekh (2005) describe PAR as a grass roots strand of action research that continues the process of knowledge production, as encouraged by Paulo Freire (1970). Grass roots, as discussed in previous chapters, refers to a bottom up approach wherein power is dislocated from the top of the hierarchical structure and redirected to those who traditionally locate space at the bottom. Within these designated parameters of PAR, the intent is that acknowledging, reflecting, and analyzing experiences of oppression may spark some form of social change. For example, in my research project all of the report drafts were circulated not only to the researchers but also to the participants. Some were very active in their critiques of the writing, others were less involved, and still one or two made no replies. The opportunity to make changes and to ensure accurate reflection of voice is one example of the grass roots approach.

Some researchers focus more on the participant ownership of the research as a means to achieve social justice and change. This ideal, according to Kesby (2005), attempts to shed the layers of patriarchal conditioning found in other forms of more traditional research, penetrating beneath well established layers for that which is hidden below so to traverse the line between theory and practice. Kesby writes of PAR as, "[participatory approaches that] aspire to reduce and circumvent the power relations normally involved in research and development and to take the notion of giving the marginalized a voice to new levels of facilitating their involvement in the design, implementation and outcomes of programs" (p. 2037). Participants gain control of power, at least theoretically, as they become involved in three keys areas of the research process: design, implementation, and outcome. Reinharz (1992) states the deconstruction of power imbalance occurs when the participants and the researchers share control, risk, and outcomes.

However, shedding the boundaries determined by traditional forms of research is a difficult task. Over the course of time, I had opportunity to become very involved with many of the participants, who frequently phoned me at home, e-mailed or requested meetings to discuss an issue or event. As most participants were unemployed, their contact information involved home phone numbers and personal e-mails addresses. In a university graduate discussion group, that I encouraged the participants to communicate with me outside the boundaries of group interview sessions was poorly received (Personal Journal Entry, February 13, 2005). Most of the group suggested I was breaking the rules by allowing participants entry into my private sphere, despite my argument that I was attempting to gain entry into their private sphere. If participants in the research project permitted me to contact them, I thought it essential that I reciprocate and allow them to contact me at my home, because I support the ideal of creating equity within the relationship and personally, interpreted equity as mutually agreeing to share phone numbers. Thus, I was unable to envision how any arrangement less than this diminished top-down regimes of power.

I did not agree with the opinions handed to me by the graduate discussion group but, I also did not argue back. Rather, I questioned my role as a researcher and worried that I did not fit the role of what a good researcher might be. I contemplated how this perceived role competed with my personal perspective about respect within research. That I remained silent within the group sessions, speaks to the power of discursive roles and how we envision right and wrong ways to approach research.

Differentiating between research logic, what rules and policies tell us to do, between what feels to be the right thing to do at the time signifies different ways of thinking. As discussed in Chapter 3, application of either logic or reasoning to attain an answer to a question can produce very different answers. There is a logic about boundaries that sets the tone for rules such as phone calls. However, in this case it felt right to me to have a mutual means of communication and home contact was one solution to a mutual means of communication. At times when participants called before I was out of bed in the morning, I questioned this wisdom but, I would take the same approach were I to be involved in research again.

I had felt quite isolated about the reaction of the graduate study group concerning the phone call issue, until I found work by Leslie Brown and Susan Strega (2005). In their discussion, termed anti-oppressive research, they write that they do not begin the process of data collection, "until all of the dogs know us, which is our way of saying no research without relationships" (p. 263). This is not to suggest all participants in research have to be personal friends, but rather speaks to the role of the researcher to gain entry into women's lives on a level which is relationship based. This approach deconstructs traditional forms of power that can occur between the researcher and the participant.

The processes of deconstructing traditional ways of research have resulted in more fluid approaches to research design. The problem that stems from a fluid design is that the process is wide open to interpretation which, at times, may leave those involved in a position of wonderment. It was my experiences that constantly asking myself *who* holds the balance of power and *who* benefits, encouraged an awareness as to what makes this research method successful, which is adhering to principles that deconstruct traditional power design, and the top down approach.

As discussed in Chapters 2 and 3 customarily those who hold the power and those with the dominant voice, control knowledge production by representing social authority structures (Swantz & Vainio-Mattila, 1988). Acknowledging hierarchy of knowledge production and deconstructing paradigms that support the top down approach is fundamental to the theoretical conceptualization of PAR. Chapter 3 referred to Freire's resistence to the banking approach to learning. Freire has also played a significant role in the evolution of PAR. Hall (2005) states he believes participatory research orginated from research work based within Tanzania. This work was greatly influenced by Freire, who visited the research site. He called for a participant focused research method that demonstrated engaged practice rather than research as a neutral dispassionate act (Hall, 2005, p, 3). The goal of PAR is to involve marginalized, or exploited individuals, or groups of peoples, throughout the research process and to identify specific underlying social issues (Hall, 1981). Transforming the social realities of oppressed people so that the beneficiaries of the research become the participants and their communities are PAR's ultimate goals (Hall, 2005). Accurate and authentic voice enables a scientific approach in which the community is involved in creating information. Hall writes that, "the researcher is a committed participant and learner of the process of research, i.e., a militant rather than a detached observer" (Hall, 1978, p. 5).Collaborative or community-based researches are equivalent to the American terms used to describe participatory approaches. Lately, another term for called, community-based participatory research (CBPR) is gaining popularity (Shoultz, Oneha, Magnussen, Hla, Brees-Saunders, Cruz,& Douglas, 2006; Ivey, Patel, Karla, Greenlund, Srinivasan, & Grewal, 2004).

4.2 Deconstructing Dominant Discourse

It is a challenge to be firm as to what PAR is or is not because of its ever evolving forms. There does evolve a sense of what it is not and this issue has been discussed in detail within work written by Robin McTaggart (1997). After studying some of his work, and preparing for this thesis, I came across an article that described how a group of young people took part in a PAR (Sandoval, Bryan, & Burstein, 2002). The journal described a PAR project designed to educated youth with disabilities about the accessibility or the inaccessibility of the public transit system and later of the local stadium. This part of the exercise, included spending a day at a baseball game whereby the youth participants evaluated the facilities for physical access. Authors claimed one outcome of the research experience was that the youth increased their self determination skills.

This study was touted by the authors as a means to teach the participants a scientific process, meaning PAR strategies, data collection, and the need for confidentiality. Sandoval, Bryan, and Burstein (2002) write, "in PAR the scientific method is used to find solutions to everyday problems. People affected by the problem, not the researchers, selected the problems to study and collect the data. By using the scientific method participants systematically test strategies to overcome perceived barriers to attaining individual and group goals" (p. 36). While this was not an academic journal, I had two problems with this article.

First, was that inaccessibility was reduced to hot dog stands that were too high for participants to comfortably place an order. On the surface I agree this was likely a point of inaccessibility. It is my position that PAR is more than studying the height of the hotdog stand. Writing the article from a narrow point of view, there was no discussion about how the height of the hotdog stand could prevent a person with a disability from being employed to sell the hotdogs. Rather, the perspective was unwaveringly from the point of view that the person buys a hotdog thus receives services, and never does this person reflect on the difficulty of being a hotdog vendor, thus a producer of services. It is my experience, that women with disabilities are not constructed by mainstream discourse to be active contributors in society, and such attitudes discourage the broader conversation that addresses the full impact of inaccessible the hotdog stand. McTaggart (1997) makes an analogy, that PAR is not about the throw of a ball, but rather, should consider all of the practices the entire ball game. It is not that McTaggart is suggesting PAR is a game, but that it should involve a broad scope of social justice.

When I think of PAR, in relation to disability and difference, I think of it as a tool that attempts to deconstruct stereotypes of disability. The article by Sandoval, Bryan, and Burstein (2002) constructed a picture of PAR as focusing on the smaller issues, such as the height of the hotdog stand, when in fact there is a much broader scope to the problem. The aim toward a quick fix of complex social issues is one of the cautions articulated by McNiff, Lomax, and Whitehead (2004). They state "thoughtful people know there is no quick-fix solutions which have lasting benefit for human striving in the interest of fairness for all" (p.2). Thus PAR, while fluid in design, cannot quickly or superficially be expected solve a multitude of deeply embedded complex social problems.

However, there was a more blaring concern within this article. The journal authors, one of whom was also a participant, spoke of all of the participants of the research by disease classification. For example, *"Jessie Sandoval is a 20-year old college sophomore with cerebral palsy majoring in political science…. Linden Aitken is a 17-year-old high school junior with mitochondrial disease… "* (Sandoval, Bryan, & Burstein, 2002, p. 36). Chapter 3 discussed how text reiterates the notion that disability is not about the person, but about some type of socially identified disease or condition. Identification by disease is a selective practice devised to mitigate the morbid curiosity of those without disabilities. Women and men with disabilities are familiar with classification and identification because this is the way many are compartmentalized by various social institutions, particularly the medical system and the government system. This labeling, answers the unasked question of, *what is wrong with her.* While we hear of millions afflicted with sexually transmitted diseases worldwide, I have yet to see a description such as, Linda Smith, 36-year-old, with Herpes and Chlamydia, majoring in law. Sexually transmitted diseases are one example of a private condition, considered taboo in most social conversation. The irony of this is that when women with disabilities are involved there are no boundaries. I have had strangers approach me in a supermarket and ask me why I am use a walker. This dichotomy is unacceptable because it reinforces stereotypes that disability is about something being wrong, as opposed to bodies and/or minds that do no meet the western ideal of what constitutes the ideal.

Sandoval, Bryan, and Burstein (2002) use stereotypic language practices, which places individuals with disabilities, specifically their research participants, apart from others in society. This tells me the authors and researchers have not shed the parameters, tools, and techniques of traditional research because the tools that determine tradition are deeply embedded structure that serve to set a normalizing baseline full of dominant discourse. While a person with a disability has contributed to the writing of the article, that individual, familiar with this type of unacceptable and degrading referencing, maybe unaware it reiterates the acceptability of social labeling afforded to *some* groups in society. Through such powerful forms of social labeling women with disabilities become their "disease" or "disabling condition".

PAR demands a higher order of questioning; a peeling back of layers to reveal hidden inner discourse (McNiff, Lomax, and Whitehead, 2004; Brooks & Watkins, 1994; Nash, 1994;). It appears deconstructing dominant discourse is easier in theory than in the field. Many times during my research, I asked myself if I was supporting dominant discourse or was I peeling back of layers to reveal the oppressive practices. Theoretical intent and what plays out in practice may not always be harmonious.

Following are some of the challenges of PAR, as related specifically to issues of disability. Reflection helps build greater understandings of this complex process, and as this thesis is about process which demands the revelation of the deeply rooted dominant discourse, disclosing oppressive influences is essential. Researchers dedicated to both PAR, and disability issues, have constructed four principles when research involves people with disability (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). The following section outlines these four principles.

4.3 PAR and Disability

We must develop a process capable of peeling back layers to discover how the lives of people with disabilities are influenced by dominant discourse. Sandra Harding and Kathryn Norberg (2005) write that dominant groups do not have the insight to, "identify oppressive features of their own beliefs and practices" (p. 2010). Because the intent of PAR is to project the marginalized voice, rather than the dominant discourse, PAR is promoted as one method for research involving women with disabilities. Theoretically, PAR provides space for voice, identifies gaps in systems, and addresses issues of social justice, social inclusion and exclusion, and the need for social change (Gatenby & Humphries, 2000; Morris, 2002). Monika Morris (2002) states that marginalized people directly impacted by research, such as women with disabilities, are usually not provided an opportunity to control the research process or outcomes. Morris states, "whoever gets to do the research drives the definition of what research is and how it is used. (p. 9). Morris encourages communities, such as the disability community, to gain control within the research process.

Research involving women and men with disabilities has been the focus of some researchers (Jason, Keys, Suarez-Balcazar, Taylor, Davis, Durlak, & Isenberg, 2004; Campbell, Copeland & Tate, 1999; Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998;

Krogh, 1998). Of these researchers, Balcazar, Keys, Kaplan, and Suarez-Balcazar (1998) have developed four principles to consider when joining forces with women and men with disabilities throughout the research process (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). These four principles are:

1. Individuals with disabilities, themselves, must articulate the research problem, and participate directly in the process of defining, analyzing, and solving.
2. The direct involvement of people with disabilities in the research process facilitates a more accurate, and authentic analysis of their social reality.
3. PAR can increase awareness among individuals with disabilities about their own resources and strengths.
4. The ultimate goal of the research endeavor is to improve the quality of life for individuals with disabilities.

The first principle is that individuals with disabilities must articulate the research problem, and participate directly in the process of defining, analyzing, and problem solving (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998, p. 106-107). Misrepresentation is a claim that many activists passionately articulate (Meister, 1999). And while there are all kinds of differences represented within the label disability, and because of past misrepresentations, there has been a demand that people with disabilities control key portions of the research process. The intended outcome is an approach increase in accuracy and in authenticity of the research. Several women in my research selected the research topic. Even more optimal would have been to have had a larger focus group discussion, but this was not feasible due to fiscal restraints and because the research topic had to be formulated prior to receiving research funds.

The second principle is that the direct involvement of people with disabilities in the research process facilitates a more accurate and authentic analysis of their social reality (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998).Louden & McCauliff (2004) write that, "authenticity is most often a term of art adopted by pundits and the popular press. When authenticity is addressed in academic circles, it is more likely to be found in rhetorical traditions than in social science inquiry. Part of the reason rests in the indeterminate nature of the construct," suggesting authenticity presents a subjective point of view (2004, p.90). It seems this second principle suggests authenticity is a socially constructed illusion and that it is difficult to predict with certainty how different profiles will be interpreted by the greater society. Therefore dominant discourse may reiterate messages about a marginalized group beyond what the group desires. For example, while I have demonstrated published text that describes women and men with disabilities by disabling conditions (Strand, 2004; Sandoval, Bryan, & Burstein , 2002) not all people with disabilities wish to be represented in such a manner.

Reclaiming identity is a fundamental practice within critical race theory. Calmore (1995) tries to reclaim the discourse for the word 'authentic'. He writes that, "authenticity implies trustworthiness and good faith in presentment. I associate it closely with integrity" (p.320). Similar to Louden and McCauliff (2004), Calmore claims the word 'authentic' is a concept constructed or manipulated by dominant discourse. Focusing on reclaiming voice through social action research such as PAR, at least theoretically, enables oppressed people to construct their own 'authentic' reality. This process of authentication, within PAR, supports the third principle that it can increase awareness among individuals with disabilities about their own resources, and their own strengths, because they are writing their own scripts (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). For example, after taking part in the primary research more than half of the participants have become actively involved in the Centre. Involvement in a political organization is one means to construct a stronger voice.

The fourth principle is that the ultimate goal of the research endeavor is to improve the quality of life for individuals with disabilities (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). There are ambiguous connotations associated with the words 'quality of life'. This is because there is a history wherein the concept, "quality of life" for the woman with a disability, has been determined by cognitive authority, discussed in Chapter 3, rather than by herself (Wendell, 1996). Thus, the context of this fourth principle is challenging.

Van der Eb et al (2004) speak of the value of promoting the community knowledge to others by creating useable materials to project community voice as well as academic voice. They state, "research must contribute to the betterment of the participating community (i.e., the project should be meaningful to the community and provide useful information to operate and sustain program interventions)" (p. 221). The words "betterments of a community" have fewer interpretable connotations than "quality of life" because emphasis lies on the larger concept of community development, rather than on the individualized, and subjective, notion of improved "quality of life". Balcazar et al (1998) write, "[PAR] encourages participants to critically reflect on their living conditions, it strengthens grassroots organizations, and develops the collective capacity of the participants to address their own needs" (p.107). But they also write, "whenever there is an attempt to change the status quo, it is always possible to encounter opposition and resistance, particularly from those who benefit directly from not changing the way things are" (p. 109). This warning indicates it is difficult to change dominant discourse.

I must emphasize that participatory approaches are not limited to discussion of disability issues. There are many marginalized groups and individuals who value participatory approaches to research. Yet some others have raised questions that call for those involved in research to reflect on participatory approaches and method designs. The following section discusses concerns from others who use the tool of reflection to challenge flaws in the ways we apply the principles of participatory approaches, in an effort to improve on the general understanding of research design and implementation.

4.4 Critiques within the Method

A grassroots approach to PAR is exciting to those previously excluded throughout the research process, however it is not beyond criticism. Discussion focuses on three areas. First is the ideology of diversity within consensus building, which can result in competing constituencies. Second, is the comparison of the theoretical ideal to the practical reality. And third is the challenge of group work and gaining accurate voice within group.

4.4.1 Diversity: Competing Constituencies

It is unlikely any group is homogenous and participatory approaches often involves partnerships with others who do not share a "common theoretical or operational definition of partnership" (Krogh, 1998. p. 123). According to Krogh, the PAR environment does not automatically value the expertise of the marginalized group over the expertise of other involved professionals. For example, just as I was finishing my research, I attended a conference about the importance of uniting universities and community groups through research. During a rather heated discussion, a person from the audience, who identified herself as a community worker, stated she had a question to ask the panel of academic experts. In regards to writing the research document, the conference participant ashed the panel if they thought academics were open to the construction of sentences written by non academics or did they, the academics, feel they had a superior knowledge of how to construct a sentence. She stated, it was her experience, that academics believed 'they' were best able to write research reports. She grilled the panel with interesting questions such as, in what situation is it possible to merge the skill and intellectual property of the academic, with the lived experience and intellectual property of the research participant, and who benefits most from such a merger. She challenged the notion that it was even possible to create ownership and negate issues of authority, power, and dominance with participants who may lack, or be assumed to lack, such skills when writing the perfect sentence is a basic tenet of university life. I thought this woman asked very powerful and pertinent questions. My university experience tells me that sentence structure, clarity of thought, and word selection is a skill believed to be enhanced by education. However, I was able to articulate my thoughts prior to this education, and readily acknowledge university writing is significantly different from the writing that is demanded by most community work. Sometimes I wonder if sentence structure is more about power than language skill.

Other community workers at that particular conference also stated it was their experience that the tugs of authority and power imbalances are real issues within the confines of PAR. McNiff, Lomax, and Whitehead (2004) write, "while most people get along amicably, serious hostilities can break out when people feel their lack of territory is threatened, understandably enough, because for many people's territory symbolizes intellectual and physical property, and therefore status and income" (p. 16). This addresses the way society value's expertise compared to the lived experience; who owns the stories of marginalized people, who gets the recognition for work done, and why. During my research, I came to the realization that conflict is inevitable. Therefore, mechanisms for dealing with conflict should be negotiated in a respectful manner and in advance of the start of the project. It is my opinion that believing conflict should be resolved by university mechanisms, policy, and procedure discounts the power of community mechanisms to reflect their voice and beliefs.

Difference will likely be present but, the usefulness of the research will differ depending on one's reason for being involved. Mohrman, Mohrman, Lawler and Ledford state that, "practical usefulness requires translation of theoretical findings to phenomena observable and identifiable by organization members so they can act on their own organization" (, 1999, p. xxxviii). Mohrman et al speak to the difference of value between the academia and community organizations. For example, differences in the value of the style and laguage used within a report document can leave one of the partner holding a theoretical document that has little organizational value. Quite frequently, it is the marginalized group that ends up with an academic styled report (Krogh, 1998).

Cooke and Kothari (2001) speak of tyranny of "decision making and control" (p. 7). They point out that some dominating facilitators arrive on the doorstep of community organization fully loaded with the answers, before the questions have been posed. Kesby (2005) confirms the value of such criticism, but state that Cooke and Kothari offer few tools to counteract such practices.

PAR is an approach to research that ideologically acknowledges difference within partnership, but does not automatically reveal ways to work within difference. Thus, it is this type of criticism that creates a dividing line between theoretical design and practical application; which is the topic of discussion in the following section.

4.4.2. Theory and Practice

PAR is about social justice, raised consciousness and how to create an environment that maintains such ideals. Despite planning, a university ethical submission, and good intention, it seems some issues are easier to resolve on paper than within the practical application. Difference within theoretical work is handled on paper one at a time, yet within the research environment many issues present simultaneously (Halse & Honey, 2005). Several issues presenting all at once can magnify its importance much more than if the issues presented individually over a period of time. Halse and Honey talk about ethical justice as an "illusionary desire" that does not necessarily fix all of the issues that arise within a research project. It is not that a university ethical submission should not be valued, but rather that all problems cannot be fully anticipated. or managed, solely on paper within the academia.

Complex social and political arenas challenge the tenet of PAR that demands the research seeks social change. For example, community disability activist Joan Meister (2003) claimed "our findings are usually shocking to people who know nothing about our lives, or who have never thought about us before. Knowing the harshness and severity of the poverty, violence, isolation, unemployment or suicide in our lives makes people cringe, disbelieve or discount us" (p. 8). Several years ago when I first read these words I thought I sensed anger, but now I read them with the understanding of how difficult it is to really create momentum for change within the context of interrelated intense social problems. Depending on how far one carries the notion of social change in my view, this ideal of

PAR has the potential to become more whimsical than practical. Halse and Honey (2005) call the ideology behind some of the theoretical intent an illusionary desire. From a less bleak perspective there is a claim that one can criticize the effectiveness of every research project, but involving participants in the process still holds a greater, or certainly no less, potential for change (Kesby, 2005).

Even if one is able to evoke change, it is unlikely everyone will be pleased with the outcome. This is because much change called for within social action research is going against what many people in mainstream society actually think is actually happening. This speaks to the fact that PAR is a political act (McNiff, Lomax, & Whitehead, 2004). For example, some people in western society believe women with disabilities are not employed because they are uneducated, and unable to perform tasks the same as someone else who does not have a disability. Thus, it becomes a political act to educate the public, to accept a new reality that women with disabilities can do tasks, but perhaps in a modified sense. McNiff, Lomax, and Whitehead write, "researchers need to understand that they are frequently in potentially politically contested scenarios" (2004, p. 15). Pushing social justice issues means both the researcher and the participant may potentially find themselves in places of discomfort.

Sandra Harding and Kathryn Norberg (2005) question the liberatory effect that is supposed to accompany research seeking social justice and change. They write that, "...[feminist researchers] have developed the controversial notions that research can contribute to producing a liberatory, transformative subjectivity in an oppressed or marginalized group and that this kind of engaged research can produce knowledge that such a group desires" (p. 2011). As researchers, when we hear the lived experiences of marginalized women, I wonder if their stories, which may be new to us, make great journal articles, but such articles may not alter the plight of the women. This is not to say there is no value to research, but when researchers speak of 'new' knowledge, I think it is pivotal to remind ourselves that the knowledge is known to the people who live with the oppression but, it is the researcher who interprets the information as 'new knowledge.' Sharing the lived experience does offer the potential for new understanding for participants, but at times researchers coming into the situation may not take away the same message as articulated by the woman who have been living the experience.

In summary this section describes some differences between theoretical intent and practical outcomes. The following section focuses on group work.

4.4.3 Group Work/Partnerships

Ownership, or buy into a partnership evokes a high level of engagement for all collaborators. But it is challenging for the marginalized community to buy into a research project and remain separate from the "university rescue mission in search of the voiceless?" (Visweswaran, 1994, p. 69). Research, when broken down into parts includes intensive study, knowledge production and informed practice (McTaggart 1997, p. 27). When the term participant, is added to the research mix, states McTaggart, clarity is reduced, because bringing together a marginalized group, and a dominant group, or representative, inevitably produces issues of difference; such as disparity in power, status, influence, and/or language (p. 28).

Ideally, PAR is designed to engage a wide collection of individuals. Essential to this type of research is participant ownership throughout the entire research process. McTaggart writes that,

> Authentic participation in research means sharing in the way research is conceptualized, practiced, and brought to bear on the life-world. It means ownership, that is, responsible agency in the production of knowledge and improvement in practice. Mere involvement implies none of this and creates the risk of co-option and exploitation of people in realization of the plans of others. This is common in community programs that are portrayed as participatory action but in reality are little more than the oppressive and unreflective implementation of some institutional policy. People often are involved in research, but rarely are they participants with real ownership of research theory and practice (1997, p.28-29).

Creating ownership within partnership can be challenging. While people may unite because of a thematic concern, there still remain issues of power within the process. Not all participants within a partnership come with the same expectations or commitments; some may be more or less passionate about the topic, and/or have a variety of demands on their time or resources. Therefore, it becomes predictable that some individuals are more engaged in the process than others. A variability of commitment was demonstrated when, in my research, report drafts were circulated. As I mentioned earlier in this chapter, the responses to the information were varying and unpredictable. Pain & Francis acknowledge that engagement of participants is key to participatory research. They write, "[the] defining characteristic of participatory research is not so much the methods and techniques employed but the degree of engagement of participants within and beyond the research encounter" (2003, p. 46). Engagement is fundamental to developing and sustaining relationships with the participants who likely are in positions of "disparity" despite efforts to the contrary (Pain & Francis, 2003, p. 46). With busy lives, illness, lack of interest, and overzealous interest, it is intricate to ensure every collaborator gains equal ownership of a project as suggested by McTaggart (1997).

Cooke and Kothari (2001) write of numerous criticisms concerning PAR. One is that too often groups are falsely portrayed as homogenous when, in actuality the group has a political agenda. Cooke and Kothari (2001) and Kothari (2001) have dubbed group actions as the 'tyranny of the group'. This tyranny happens when the group determines dominant norms and practices, and values consensus over differentiation. Kesby (2005) counteracts this claim stating, collaborators are not neutral players, they have a role that requires each individual to find a place within the group whereby they learn to project their voice and self police group dynamics. Evidence of group control of the topic surfaced once in my research. One mother within the group wanted to include issues of motherhood as barriers to employment but others, there was only one other mother, in the group were very resistant, and suggested the participant was straying outside the intent of the research. They indicated those issues of motherhood, and employment, were separate from issues of women, disability, and employment.

4.5 Summary

In summary, PAR is a qualitative type of research which offers a wide range of approaches intended to build relationships with identified communities. To ensure a closer reflection of voice, PAR includes participants throughout all of the research process. Including participants in all of the process is a major shift from traditional research because, theoretically, such inclusion disperses power so that participants, community partners, and researchers equally control the outcomes. At the same time PAR ensures some degree of shared values and social action with community members (Jason, Keys, Suarez-Balcazar, 1998; Taylor, Davis, Durlak, and Isenberg, 2004; Balcazar et al, 1998; Reinharz, 1992). PAR has the potential to reconfigure traditional boxes (Chaudhary, 1997). One problem is that reconfiguring embedded discourse takes time and patience so that the change may not be obvious or measurable within expected outcome of every research utilizing participatory approaches.

Feminist PAR is a social inquiry, that enables action to occur with a level of consciousness about underlying assumptions (Wadsworth, 1998). Acknowledging the pervasiveness of social, and cultural, patriarchal discourse, one must always reflect back, and check for hidden assumptions and attitudes. Wadsworth visualizes this form of social inquiry as never-ending cycles of questions, reflection, analysis, fieldwork, and plans for action. PAR represents endless cycles because the process elicits infinite questions that require the process to continue on and on. PAR is not, and should not be, a neatly structured research method that has researched full maturity. As a research process PAR is emerging with many possibilities waiting discussion and discovery (Walton & Gaffney 1989). But it is also not a scientific process whereby considerations such as outcomes planning and methods of data collection fall outside of any scientific standard (Whyte, 1989). These considerations are in part what make PAR a difficult concept to visualize. The process of change and knowledge is an integral part of the design, yet the design itself is fluid and developing.

The most valuable lesson I have learned over the course of this case study, and the writing of this thesis, is that participatory approaches to research are intricate because of the inclusiveness of its design, and the complexity of the social situations of many people attracted to such a research design. It is apparent that issues of difference and representation do influence the process of participatory action research. The following chapter 5, presents my research findings and provides a discourse analysis of some key points of interest highlighted throughout the research.

CHAPTER 5

Discourse Politics and Control

Individuals are the vehicles of power, not its points of application.

Foucault 1980b, p. 96

Feminist critical discourse analysis is an intricate multi disciplinary method of research that examines paradigms of power and social injustices through the application of fundamental values of feminist methodology. Critical discourse analysis is a method of research supported by academics and activists who wish to explore, understand and ultimately influence the consequences of social oppression, dominance, and inequity (Lazar, 2004). I purposively selected the following four points of interest that I felt best articulated difference among varying historically constituted knowledges and practices. These points originate from the primary research project and include:

1. Participant Selection
2. Negotiating the Rules of Financial Management
3. Ethical Concerns and Community Resistance
4. Varying Interpretations of University Research Policy

This chapter expands on the first two findings, participant selection and negotiating the rules of financial management. Intermingled with the data is a critical discourse analysis. Chapter 6 addresses the last two points, ethical concerns and community resistance and varying interpretations of university research policy. This case study responds to the ways embedded issues of difference and representation influence the participatory action research.

5.1 Participant Selection

Chapter 4 discussed examples of discursive social practice, specifically Foucault's rendition about the evolution of mental institutions (1965). The problem with discursive practices is the lateral effect, as the evolution of these institutions created ideologies about mental health, criminality, and set standards for normalizing practices (Devine, 2000). Normalizing practices are fluid and ever evolving yet such influences emit enough power to stigmatize some individuals and groups of people. Over time stigmatized people have become objects of social and governmental control. In an effort to deconstruct discursive practices, that marginalize, and oppress, approaches to research has evolved such as PAR.

Participatory approaches to research construct teams from which the research evolves. The initial team in this case consisted of the community co-investigator also the Executive Director of the Centre, the academic co-investigator from a Canadian university and me, the primary investigator. Ethical approval from the university was a stipulation of the national funding agency and mandatory for research involving the university. Following the ethical approval, primary and co-investigators were ready to complete the research team and by inclusion of women with disabilities and a research assistant, thus participant selection began.

EXCERPT 1

> (Invitation and Information for Research Participants)
>
> The research team will select 10-12 participants from those who indicate interest by completing the attached form. Not everyone who wants to participate can be included in this study because it is not practical to have a larger group given study objectives. Participants selected will be as diverse as possible. Diverse refers to various kinds of disabilities, ages, work experience, and knowledge of Adaptive Technology. No one will be discriminated against because of disability, race, or sexual orientation. (Appendix A)

This Invitation to Participants was written, by me to gain ethical approval for my research. At the time, I was very much aware of a community way to issue an invitation from the more formal way advised by the academic co-investigator. My conflict focused on how to do good research and how not to have the language so beyond what was commonly used within the community. Most of this preparatory work happened within the university, where I felt there was little acceptance for the informal community way of doing. As introduced in Chapter 2, work involving disability oppression has not been a topic for frequent academic study (Oliver, 1990). Therefore few templates of understanding disability, as a historical community, and a category for analysis, were available (Garland-Thomson, 2002).

As a result, this excerpt tells me ownership for the decision making process for the participant selection lies with the research team. Reflecting back, this approach is a traditional approach to research whereby the research team in control. In Chapter 4 PAR is described as a method of research that attempts to shed the layers of patriarchal conditioning found in other forms of more traditional research in effort to traverse the line between theory and practice (Kesby, 2005). PAR is specifically designed as a means to reduce and circumvent power relations so that power is theoretically reconfigured and redistributed equally among all involved.

Beginning the selection process with the research team in control is not an approach that reduces or circumvents concerns of power inequities. Rather, this approach affirms control of the research by the research team. It supports the notion that it is a conventional wisdom that the researchers control the participants either in regards to numbers manageability or through the necessity of participant diversity. Jane Holmes calls this approach the "taken-for-granted, self-evident truths" (2004, p. 32).

> EXCERPT 2
> (Personal Journal Entry, November 15, 2004)
>
> I am surprised at the way some women are approaching me. Today a woman came up to me and said I have read all the information and I think I will agree to help you out with your study.
>
> [My surprise was that participants were to fill out application forms and the team was going to select on the basis of diversity of age, work and Adaptive Technology experience.] I am beginning to feel uncomfortable with the selection process. I know because of the number of responses it is possible this woman will not be selected by the research team.

Excerpt 2, describes my reactions when one prospective participant approached me as I was volunteering at the Centre. The woman firmly informed me of her intent to participate. Discussed in Chapter 3 was how dominant discourse sets boundaries that determine what becomes natural or normative. The woman who approached me was acting from her perspective of normative; meaning that she presumes that she determines whether or not she will participate in the study. She does not consider this a role of the researchers because this woman, well steeped in the structure of the Independent Living philosophy (Chapter 1), assumes a grassroots approach whereby women with disabilities choose with whom they will share their stories. Taking an individual constitutive approach to power (Deveaux 1994), the woman volunteers to participate, thus she assumes ownership of the decision making process.

Conversely, I too exhibit normalizing practices as I presume it is a task of the research team to select participants. That I thought this method of participant selection was an optimal approach demonstrates how my conformity to traditional research practices supports institutional authority structures (Holmes, 2004). It is problematical to look back, as reflection leaves me a sense of wonderment and difficulty justifying this approach. Lazar writes, "there is a need for feminists to be critically reflective of our own theoretical positions and practices lest these inadvertently contribute to the perpetuation, rather than subversion, of hierarchically differential treatment of women" (2004, p. 15). Discourse analysis is essential because reflection back onto the process highlights mistakes made, therefore diminishing the likelihood the action will be recycled into other work.

Excerpt 1, illustrates a normalizing practice that served to empower the research team. Excerpt 2, depicts the beginning of my recognition of a different normalizing power that has the potential to deny the participants their power. Excerpt 2, also illustrates how participant rejection of the rules is one means to negate researcher authority. Choosing research participants is a traditional approach to research that does not fit well with the theoretical structure of PAR even if the justification for such an approach is to mitigate the researcher need for manageability and diversity. It does not fit well either, with the philosophical intent of Independent Living. I researched feminist literature for suggestions about how to engage participants into the process.

Reinharz writes,

> In feminist participatory research, the distinction between the researcher(s) and those on whom the research is done disappears. To achieve an egalitarian relation, the researcher abandons control and adopts an approach of openness, reciprocity, mutual disclosure and shared risk. Difference in social status and background give way as shared decision –making and self-disclosure develop (1992, p. 181).

Reinharz (1992) speaks of an egalitarian relationship. Abandoning control and approaches of openness require rejections of ways of doing that are familiar. I do not think the Independent Living philosophy is the panacea to disability oppression; but I do envision the approach, as a means to change, or at least, challenge dominant perspectives. What may appear to be a preoccupation with this approach, is more so a reflection of raised consciousness that I personally experienced as I began to comprehend the intricacies of the concept. The approach of the woman described in Excerpt 2, challenged me and my traditional way of doing. She believed it was her right to decide whether or not she would support the research. There was more than one challenge to the way we were selecting participants.

Another woman takes the time and writes me an e-mail that again expresses some concern about the method of participant selection, but in a different manner.

EXCERPT 3
(Participant E-mail to Michelle; November 18, 2004)

> It looks as though I don't fit any of your categories.

"I do not fit your categories for participant selection" *(Excerpt 3).* When I read the e-mail I was extremely disturbed that the woman, who I did not know well at the time, interpreted information she had read concerning the project as first determining categorizations, and second as discriminating amongst the categorization. Chapter 3, identifies some of the discriminatory ways individuals with disabilities are classified. It also presents evidence that demonstrates how media identifies people, not by achievement, but through distinction of disability. I realized the woman perceived the wording as reiterating this stereotypical discourse.

van Dijk (1993) describes a process where by elites transfer down oppression onto the lower class; from the hierarchical construction of this research it seems researchers had opportunity to transfer such approaches onto the participants. "Your categories" highlights the system of categorization (Excerpt 3). The prospective participant counters this authority by saying "I do not fit". Again, she challenges what she perceives as a system of stereotypical categorization.

EXCERPT 4
(Participant E-mail to Michelle; November 18, 2004; continued)

> I worked for over 30 years and used technology which was available, attended university doing several things, trained and worked as a professional computer programmer before being employed with the federal government, latterly in the Employment Equity Program of the Public Service Commission of Canada.

Most women with disabilities are unemployed, under employed or too ill to work (Feika, 2003; Office of Disability Issues, 2003; Office of Disability Issues, 2002; Federal, Provincial and Territorial Ministers Responsible for Social Services, 2000). The woman sending this e-mail states she does not fit any categories because she has lots of work experience. van Dijk (1993) writes that dominant discourse forms traits of marginalized groups. As discussed in Chapter 3, dominant discourse does not construct the woman with a disability as holding a revered (at least from my perspective) job with the federal government. A counter power develops when woman identifies her long-term employment as a point for exclusion from the research. The image of a self sufficient employed woman with a disability does not fit the traditional stereotypical discourse.

> EXCERPT 5
> (Participant E-mail to Michelle; November 18, 2004; continued)
>
> However, I have taken early retirement and spend much of my time doing volunteer work which does necessitate the use of A.T.[Adaptive technology]
>
> However, it would seem that anyone with past experience does not come within the jurisdiction of your mandate, which is unfortunate.

"However, it would seem that anyone with past experience does not come within the jurisdiction of your mandate which is unfortunate", emphasizes the supposition that the researcher is setting research parameters through participant selection. Presumptions that the research team hold authority to predetermine mandates supports the claim that traditionally, disability groups within partnerships hold a secondary position (Boyce, 1998). The woman's response presumes the secondary role, as it is the researcher who is choosing participants, yet she points out that there is a value to having a broader lens when determining who represents a woman with a disability. This speaks to the interconnectedness of power, which Weedon describes as a "dynamic of control, compliance, and lack of control between discourses and subjects" (1997, p. 110). Disability feminism claims that the prevalence of stigmatizing normatives, both social and cultural, contribute to our representation as women with disabilities. Including this woman in the research added to our conversations about why some women with disabilities find work and why others cannot.

> EXCERPT 6
> (Ethics submissions, 2004)
>
> This research team will recruit women with disabilities from the St. John's and surrounding area. The team will select a diverse group of ten women who indicate their interest in participating in the study by responding to the recruitment call. The purposive method of selection intends to bring together women of varying ages and disabilities, employment, educational and training experiences, and knowledge and experience with AT. There will be no discrimination based on disability, ethnicity, race, or sexual orientation. (Appendix B)

Removed from the process, this period of reflection enabled me to develope a different perspective. I interpreted the language in this ethical submission as again replicating a hierarchal approach, in which the researchers are located at the top and prospective participants at the bottom. Suggesting the research team will *purposively select* places the researcher in position of authority for two reasons:

1. The person who holds the power is the person(s) who determines voice.

2. Purposive participant selection involving women with disabilities holds potential for discrimination

The person who holds the power is the person(s) who determines voice (Charlton, 1998). Traditionally the researchers choose participants, which means we, the research team, holds positions of power over women interested in taking part in the research. This does not fit well with the theoretical paradigms of PAR described in Chapter 4. Neither does this approach fit with concepts of providing voice to marginalized groups (Boyce, 1998). van Dijk (1993) refers to this approach as a naturalizing tactic. The research team subtly assumes responsibility for organizing and planning. That no one challenges this approach speaks to the power of the naturalizing ways that enables women, specifically women further marginalized by the oppression of disability, to willingly accept this approach.

Khanlou and Peter (2005) write that, "within particular communities issues can also arise with respect to the fair selection of participants. Interested members of the community should be given meaningful opportunities to participate, especially if they have been underrepresented in the past" (p. 2336). Working within a theoretical environment that emphasizes the deconstruction of hierarchal relations of power it seems the research team, despite good intent, veered into traditional approaches. Participant selection methods reinforce discourses of researcher power even though the approach is participatory based.

The second problem is that despite use of conventional wisdom of including the statement "there will be no discrimination based on disability, ethnicity, race, or sexual orientation" (Excerpt 6) this method of selection, when referring to women with disabilities, holds potential for discrimination. The researchers did not intend to discriminate based on disability but have created potential for conflict by claiming the right to purposive selection. For example, the community co-investigator asked me what would happen if two or three women with the same disability filled out an application form to participate in the research. In an effort to gain diversity of participants I replied we would select only one, possibly two of the three women. After some discussion we concluded that a woman excluded from the project based her type of disability offered potential for discrimination. In Chapter 3 and 4, discussion arose describing predominant social classification systems which favour some disabilities over others. Knowing this history, I feel it is reasonable to predict a purposive selection of participants, in a quest for diversity, does leave potential for a woman to feel discriminated against because of her disability. Such an approach inadvertently reinforces discriminating selection practices often experienced by women with disabilities in other areas of their lives. Hughes (2005) writes that distinctions between 'normal' and 'pathological' discursively constitutes disability of the body and/or mind as a deficit. Besides reinforcing selection processes found in the every day lives of women with disabilities, purposive approach identifies disability, as a 'deficit,' as a deciding factor for participation.

Understanding that one premise of PAR is to promote egalitarian relations (Reinharz, 1992) one has to ponder if this is possible when the researchers position themselves in a place of authority by choosing who will participate in the project. Purposive selection, through an application process, suggests a means of setting boundaries through hierarchy rather than a process of power deconstruction even though unintentional. Selection or rejection of participant applications demonstrates the power of the research team. If knowledge is inherently bound to perspective, widening one's perspective can allow a broader scope of how to approach participatory research.

Abandoning control and adopting a flexible approach is imperative (Reinharz. 1992). Recognizing that women challenged the research for different reasons the team adapted its point of view to respond to the varying concerns of the women. Acknowledging potential for discrimination, and recognizing flaws in the participant selection process, all women who expressed interest were invited to participate in the research. Inviting everyone who expressed an interest in the research was one way to improve the flawed participant recruitment process.

One could also take a completely different approach to participant recruitment. I visualize issuing an invitation to all women with disabilities within a specific area to attend a meeting about a topic. This initial meeting informs women of the commitment and promotes further discussion about process and achieving goals. Funds may limit participant numbers or require innovative thought on how to be inclusive. If the goal really is to relinquish control, coming to a selection agreement with prospective participants, such as drawing names out of a hat at a group meeting, avoids an authoritative selection process. In conclusion, the argument put forward here is that unintentionally the process of purposive participant selection presents the potential to include some and exclude others.

Reflecting back on the descriptions of PAR it seems an integral part of the process is first to develop partnerships (Hall, 2005). In fact Hall states that in a 'truer' form of partnership there would be no distinctions about positions, and everyone involved would be a researcher. This type of approach would be time intensive and necessitate committed involvement of all collaborators. Truer forms of PAR require a considerable shift in reconfiguring what research can look like, a reconfiguring of the ethics submission, and likely an increased number of ethics submissions. Within community and academic collaborations I am unconvinced that either the community or the university has structures in place capable of supporting such fluid types of time consuming research.

Despite my dismay about the selection process I think the actual process of PAR did work well because the research team responded to input from women and revised their ways of doing. The following section articulate issues around control of research funds within PAR.

5.2 Negotiating the Rules of Financial Management

Numerous researchers articulate the complexity of working with people and groups who represent disability issues (Taylor, Jason, Keys, Suarez-Balcazar, Davis, Durlak, & Isenberg, 2004; Lord & Church, 1998; Boyce, 1998; Balcazar, Keys, Kaplan, Suarez-

Balcazar, 1998; Campbell, Copeland and Tate, 1998; Krogh, 1998). Lord and Church write that, "for consumers with disabilities coming to the table with more powerful potential partners brings enormous risk." (p. 114). Despite approaches to research such as PAR, the literature indicates there still remains a significant challenge to create an environment that offers potential for power equity.

Kari Krogh (1998) states there are a number of difficulties researching within community partnerships, particularly those inclusive of women and men with disabilities. Three in particular challenges are:

1. There may not be a shared sense of partnership.
2. People with disabilities often feel their expertise is not accepted by professionals.
3. Representatives from marginalized groups may be co-opted and exploited by more dominant partners (p. 123- 124).

Krogh (1998) addresses difference among various disability organizations. She writes that, "those that employ a Charity Model of disability may assume that a participant who has a disability should be a passive recipient of assistance rather than an active and critical member of a work team" (p. 127). She states that groups that operate within the medical models of disability (Chapter 3) are, in her experience, much more likely to be passive about who controls the money. However:

> People who employ an Independent Living Model of disability, alternatively, may become frustrated by the restrictions that are placed on consumer participants. For example, people with disabilities may not be allocated the responsibility of administering funds of a community

> partnership project. These belief systems can be represented and reinforced within both the institutional structures of society and partnership practices (Krogh, 1998, p. 127)

Not surprisingly, who controls the research funds was a topic for much discussion during the first half of the project. At no point in time did the research team chat about these issues as a group, and I think I assumed the university would manage the money. As the project became more organized, and it was almost time to include participants, I visited the Office of Research at the university. Following this visit I e-mailed my advisors at the university. The community co-investigator was on the verge of a leave of absence at this time so she was not involved in this conversation. I wrote:

> EXCERPT 7
> (E-mail: From Michelle to academic co-investigator and independent academic advisor, Oct. 14, 2004)
>
> I spoke with, a person at the Office of Research several times today. We have several choices about funding. The university can hold the funds, my name and a supervisor's name will be on the fund. Each will have equal access to withdraw. Co-sign is an administrative person. This system does not charge a fee but does have a well defined structure (as in rules & regulations). Or the community can hold the funds and administer book keeping. Arrangements would be similar except it would be a relationship between myself and the Centre.

I interject here to highlight the options presented by the Research Officer. There were no options that combined the university and community; missing was any sense that we could all work together. Thus, this critical discourse analysis indicates an egalitarian approach, as suggested by ideologies of PAR, are not apparent within these choices. The academic co-investigator replied:

> EXCERPT 8
> (E-mail: From academic co-investigator to Michelle, Oct. 14, 2004)
>
> "I suggest you keep the funds at the university. (e-mail 14102004).

Another person from the university wrote:

> EXCERPT 9
> (E-mail: From independent academic advisor to Michelle, Oct. 14, 2004)
>
> I agree with academic co-investigator unless University regulations restrict the hiring and salary of any research assistant.
>
> [The research office] would answer this. I would be happy if XXXX accepted the co-signing role.

External research dollars coming into the university by a researcher builds reputation. University management of funds also ensures their appropriate management. Knowing I have no problem managing budgets, and acknowledging the reading by Krogh (1998) that states the disability community rarely controls the funds, I thought we had two options. Option one was that the university would administer the funds, with signing authority given to myself, and the academic co-investigator, with a third signature from a university employee. The problem with this approach is that it completely removed the community investigator from any official control over spending, as predicted by Krogh. A second problem, with the university managing the funds, was that the funding agency had awarded the grant in my name. The university, unable to accept a third party cheque would need the funds reissued back in the name of the institution. A phone call to the funding agency confirmed they had chosen this approach deliberately.

Option two was to have the community co-investigator/agency hold the funds with a similar check signing arrangement as the university, only within the community. This would bypass the academic co-investigator, and remove funds from the university. In one sense such an approach deconstructed normative thought that the university should administer funds; but it did not enable an egalitarian approach. Discussion about funds was happening the same day I tendered my resignation to the Board. It was also the second last day of work for the community co-investigator. I chose not to immediately inform the Centre about the university perspective on the money issue. The following e-mail provides a more detailed explanation why I made this choice:

> EXCERPT 10
> (E-mail: From Michelle to academic supervisor, October 14, 2004)
>
> I deliberately did not cc this to the Centre because there might be some big argument for or against one system that I am unaware of and I did not want to create more conflict. I feel somewhat guilty doing this because I feel in a sense it cuts them out a bit from decision making.

The application of university research standards requires work within particular parameters. There did not seem to be a way to achieve circumvention of power and egalitarianism without more flexible interpretation of policy. This supports Robin McTaggart's argument that "people often are involved in research, but rarely are they participants with real ownership of research theory and practice (1997, p.28-29). This realization was discouraging, and further supports a point made by Halse and Honey (2005), that ethical justice as an "illusionary desire" that does not necessarily fix all of the issues that arise within a research project.

I met again with the Director of Research, who had made inquiries within her network about the funding agency, and informed me the university way of doing was indeed different from the community way of doing (Journal entry, 11012004). Administering funds through the university necessitated that all participants receiving an honorarium would have to provide a social insurance number and sign T_4 slips that would be kept on file at the university for 7 years. I was unsure how this fit my conceptualization of confidentiality and participant anonymity. Reimbursement for transportation costs was another concern. The university reimbursement rate, catering to drivers, was paid in cents per kilometer. The participant rate, catering to Paratransit users, demanded reimbursement of flat rate costs of $5 return trip.

University protocol did not fit with participant need. It appeared negotiation for the university to meet the need of participants was limited by interpretation of policy. I sensed tension with the community co-investigator about how this issue would resolve. Holmes writes. "the more powerful person in an interaction typically gets to define the purpose or significance of the interaction and influences the direction in which it develops" (2004, p. 32). In this case, respect for participant need demanded alternatives. Participatory approaches enabled choice but choices within the academic-community structures seemed to exclude shared responsibilities or power.

The Director of Research directly e-mailed her advice to people involved in the research within the university.

> EXCERPT 11
> (E-mail: From the Office of Research to Academic co-investigator and cc to Michelle, Nov. 1, 2006)
>
> Michelle and I met earlier today about her \$5,000 grant from the funders - which she has been awarded as a result of her proposal. (Name of research)
>
> This grant was applied for by Michelle and has been awarded to Michelle, as opposed to the University, and the grant agreement has been prepared by (funder) accordingly. As I explained to Michelle, the University has a firm policy (I confirmed this with Financial and Administrative Services) of not administering funds on behalf of individuals. In order for the University to administer this funding, Funder would need to recognize University as the grantee, with Michelle as P/I (together with supervisor) and Funder would need to change the grant agreement to reflect this. Michelle has already raised this with the sponsor and they are not supportive of this change.
>
> For this particular project, however, Michelle does have a community partner which does not have the same position as University regarding administering funds on behalf of individuals. Which means, of course, that she does have some choice in how to handle the administration of her grant to both meet the requirements of the sponsor and to allow her to not have to take all the responsibility for administration of the funds. Another budget item that might be an issue with university financial policy and procedures (although I haven't checked into it with Financial and Administrative Services to be absolutely sure what flexibility we would have), is the flat rate amount for use of own transportation, payment for use of home office and the rates for various services required under the project.

Israel et al (1998) claim that theoretically, PAR creates an environment whereby participants and researchers share equal power and control throughout all of the research processes; including design, implementation and outcomes. It seems to me discussion about distribution of power traditionally focuses on the structure of the research, rather than how to navigate practical aspects such as equitable control of the funds. While the university has reasons for its strict research funds management, it does not seem to fit with the goals discussed in Chapter 4, concerning community-university partnership.

There are a few other aspects of the budget that, owing to strict requirements on the University, that we wouldn't have flexibility on if we were to administer the funds. An example, would be the requirement of a social insurance number in order to pay out honorariums. A note here: I know several women who have been deemed unemployable all their lives and have never acquired a social insurance number.

Recently I asked with the Executive Director of the Centre to clarify the problem with the providing the social insurance number to the university.

> EXCERPT 12
> (E-mail: To Michelle from the Executive Director of Centre, March 7, 2006)
>
> By using social insurance numbers, people have access to all sorts of personal information about consumers. It is unwise to provide SIN's for any reason other than to an employer.

Thinking there might be a possibility of circumventing this university protocol through university policy about risk to participants, I examined the possibility. The policy states, "research participants must not be subjected to unnecessary risks of harm state the risk is not acceptable" (university, policy 11). This policy has very vague connotations and it appeared unclear who gets to determine risk. I wondered if the university policy structure would accept that risk for some participants would be providing the university their social insurance number. I did not explore this further because I knew providing social insurance numbers was considered a risk for participants from the Centre's perspective. There was potential for more conflict if the ethics review committee did not agree. If this were the case I was unsure how I would proceed.

> EXCERPT 13
> (E-mail: From the Office of Research to Academic co-investigator and cc to Michelle, Nov. 1, 2006 ; continued)
>
> I do feel that in this particular case, Michelle does have options in how her funds will be administered and only one of these options would be to have the funds administered through the University. Owing to the stance of the sponsor and budget items and rates that have been already approved for funding, I am not sure that having the funds administered through the University is her best option at this point. Regardless of her final choice, however, we did discuss a few amendments regarding dates and schedule of payments that she should raise with funder.

The university research officer was open to various means of having the funds managed. I did not feel at all dominated by this individual. But several times in this chapter and the next I refer to my status as a student. In an official sense the research office directly addresses the academics, I am sent the note as a side line but never is the Centre part of the conversation. This arrangement demonstrates university hierarchal structure that I refer to a number of times in this chapter and the next. I had difficulty visualizing a partnership, whereby one partner appeared totally self regulatory. This self containment made it challenging to include the opinions expressed within the disability community.

Upon hearing the advice of the director of research it was suggested by an academic advisor that funds be administered through the community (EMH Nov 01 004).

> EXCERPT 14
> (E-mail: From academic co-investigator to Office of Research, cc to Michelle, November 1, 2004)
>
> Thanks so much for advice on this. If nothing else, Michelle has had an opportunity to learn a lot about grant administration. I agree that the university is not the best "partner" in this; I am sure Michelle can go to the community partner more aware of the legalities of grant administration.

Funds management became an issue decided by conflicting policies and how these policies would negatively impact participants. Had we been addressing a substantial budget it seems to me where to manage the funds would have been a considerable hurdle to navigate.

Supported by the book keeper, I managed the funds at the Centre and provided financial updates to the funding agency, and the academic co-investigator and the community co-investigators at the half way point, and upon project completion. I was really pleased with this arrangement. The work progressed well until it came time to print the final report documents. In the spring of 2005, I was preparing for to have our report printed. I received quotes from the university printer, and then visited the university graphics and design office, where I spoke at length with the staff. Here I was introduced to the power of graphic design. I found the university format for its annual general meeting report (2005) to be bright, inviting, and easy to read. I took samples for the participants and co-investigators to look at.

Everything was going fine until I received a call form the Women's Studies Office telling me I could not receive the university printing services for my research without a FOAPAL (a type of payment system). A FOAPAL enables access to university services and without this access the service is denied. Undaunted, I made my way over to one of the Dean's offices to get a FOPAL. I was informed by Officer of Finance of the department, that it was impossible for me to obtain a FOPAL because the university was not managing the research funds. I called the academic co-investigator, Graduate Studies, my department head, and the Office of Research, but no one had any information about how I could get a FOPAL. I must make it clear that money was budgeted for the report document. The problem was not that I wanted the university to pay for the printing. Rather, it seemed impossible to get a university service unless the money was under university control. Up until this point, I was unaware that this was a consequence of the community managing the funds within the community-university partnership.

> EXCERPT 15
> (E-mail: Office of Research to Michelle, April 29, 2005)
>
> I know you feel frustrated at not being able to have your project report printed at University and I hope you will understand that the particular institutional policy at issue here is not intended as lack of support to you as a student in one of our programs nor as a researcher engaged in a community collaborative research project.
>
> The key issue at hand is that a conscious decision was taken not to have the funds for this project administered through University. I remember we did together weigh the pros and cons of having the sponsor redirect these funds from you personally to the institution and we took what I felt was a reasonable decision in favour of not having the award redirected to University. University does take care to act responsibly in not providing its services for outside work, and the institution is open to being taken to task on this, so there is a pretty rigid policy around things like printing services when University funds are not involved.

The university pays for its services through grant money managed by the university or government allocation of funds. Despite the partnership, inability to access the university printing services was the consequence of not being able to pay through either of these venues. The impact on the research was that the expertise of university printing services and those who know the rules (such as how large the university logo can be on a document) were not available. Printing costs quoted by the university were significantly lower than all other quotes prepared (Journal entry April 28, 2004). Despite being a partner in the research, the university was apparently unable to share a service otherwise available to other researchers at the institution.

Momentarily, the added task of going out and finding professional printing services seemed insurmountable. The research assistant and I had to quickly find reliable printing services, make appointments and visit each establishment for cost comparisons. The funding agency contract stated their final allotment of money would be dispersed upon receipt and approval of the final research report. Having to pay for the printing upon delivery of the report, and having no personal access to a large sum of money, I anticipated a considerable dilemma. At that time I was very disillusioned with the term 'community-university partnership'.

The problem was resolved when the community co-investigator paid the printing costs. When funds arrived, the Centre was reimbursed. The e-mail continues:

> EXCERPT 16
> (E-mail: From the Office of Research to Michelle, April 29, 2005; continued)
>
> I am not, unfortunately, able to accommodate your request to create a FOAPAL specifically for this printing job. I am pleased that you were able to obtain some advice regarding your formatting/printing needs and from the consultations that I have done regarding your request, I trust/hope that the inconvenience to you in having the report printed externally will not be extreme. I do recognize the initiative that you took in applying and being awarded these funds and I realize that the work you have undertaken as a result will support the work you are doing in your academic program. I am also pleased to note that you have reached the report stage of your project and hope that you are pleased with its outcome.

> Thank you for bringing the matter to my attention. I am involved in the review of institutional policies and procedures as they impact on research so it is helpful in that context to be aware of situations such as this one. As an institution, we are constantly adapting to the changing research and research funding environment, but we are a large institution and changes take time and careful consideration (EMC 04292005).

Despite this, the legal department at the university gave permission for the university logo to appear on the cover of the research report as the university was a partner in the research. At this point I felt as if my relationship with the university was similar to a male dominated patriarchal marriage whereby the husband (authority) denied me (no authority) access to anything he did not control. In actuality, in regards to management of funds and access to university service the choice that eventually became apparent in this case was total control of the money and access to services or no control of the money and no services.

Resistance to power is, according to Weedon (1997), a first stage in creating new or alternate forms of knowledge. This is the reason for the inclusion of this section. The lack of a FOAPAL was the result of choosing to disperse the funds through the community rather than through the university. Despite the establishment of a partnership this demonstrates the consequences of working beyond traditional approaches to research. It is not about good or bad choices but just choices in general and how process impacts choice and relationships.

Chapter 6 continues the discussion about partnerships, politics and PAR.

CHAPTER 6

Discourse: Politics and Partnership

> Whoever gets to do the research drives the definition of what research is and how it is used (Morris, 2002, p. 9).

The discussion continues from Chapter 5, whereby this case study, through discourse analysis describes how issues of difference and representation influence the process of participatory action research (PAR). The following chapter consists of two parts. The first section describes a conflict and the resolution. The conflict focused on the appropriateness of my holding a Board of Director's seat Centre, while the primary investigator of a research project involving the Centre. A shorter second part of the chapter examines three portions of the research policy of the university. It was these policies that the research team struggled to apply to resolve the Board issue.

6.1 Ethical Concerns and Community Resistance

Very early into the proposal stage, I anticipated a difference of opinion, when the academic co-investigator requested that I resign from the Board of Directors at the Centre. She envisioned a Board position, at the Centre, as a site of power that potentially might intimidate perspective participants. The community co-investigator told me that she would not support my resignation, because the research was unrelated to my Board work. She envisioned the position as an indication of community involvement, suggesting an understanding of community issues.

The community co-investigator writes:

> EXCERPT 17
> (E-mail: From the community co-investigator to Michelle, May 14, 2004)
>
> I don't see any conflict between doing this research and being on the board as you are not doing this in the role of board member.

Numerous discourses are at work here. The community co-investigator and I had known each other for several years as I organized various workshops and events that happened at the Centre. According to the constitution of the Centre the Executive Director is directly answerable to the Board, specifically the Chairperson. While I assumed a Board position, a sense of power over the Executive Director was not paramount within my conceptualization of our relationship. This may have been an illusion on my behalf.

My relationship with my academic co-investigator differed considerably. This association stemmed from contacts with graduate school. As an older person engaged in university protocol frequently, I perceived myself as not fitting in well in part due to my intense engagement with disability oppression. Perhaps I entered graduate school looking for answers, without acknowledging the value of my personal experiences. With that said, the university functions within a hierarchical paradigm of authority, in which graduate students are very close to the bottom.

Personal roles aside there exists much larger issues. Driving the conflict of the Board position was competing constituencies within the research team. It makes sense, from the academic perspective, that the researcher does not place herself in a position of power over participants, or anyone else that might detract from her ability to be engaged in the research process. Likewise, it makes sense that the Centre, based on an Independent Living model, would resist outside interpretation of what constitutes power within their community, and would deny my need to resign. Both points of view reflect differing bodies of historically constituted knowledges and practices.

Theoretically, the conflict is called intertextuality. Mary Talbot writes, “the term intertextuality expresses a sense of blurred boundaries, a sense of a text as a bundle of points of intersection with other text” (2004, p. 168). Thus conflicting points of view are not about who is right and who is wrong but rather about taking a perspective with the background knowledge of what each individual constitutes as right and wrong way of doing. Robert Kaplan (1990) uses the analogy that critical discourse analysis is like thick plywood, comprising many thin layers merging at different angles to one another. Each thin layer represents a point of view which at random times conflicts with points of views of other people. It is not as much opposing camps, but rather a mesh of ideologies that at times work well together yet other times are antagonistic. Not fully acknowledging the impact of the conflict, I frequently conceptualized my position as primary investigator as smoothing over various tie-breaking decisions.

Disability studies, in the context of feminist theory, are designed to support a broader understanding of society (Linton, 1998). Part of this broader understanding is appreciating the power of identity. My intense personal struggle with removing myself from the Board was in part due to the fact that I felt my engagement with the disability community was fundamental to my understanding of disability issues. It is at the Centre that I feel 'at home.' It is the discriminatory experience of becoming a person with a disability that has bonded me to a whole group of people who have also experienced similar, but different oppression. In Chapters 3, I speak of disability discrimination, but it was not really until I critically analyzed this issue, that I truly came to appreciate the binding nature of discrimination. My analogy for this feeling would be similar to the commonality women may feel toward one another. Garland-Thomson writes, "a feminist disability theory can also highlight intersections and convergences with other identity-based critical perspectives . . . (2002, p. 21). There was a space in which I needed to uphold good research practices, and also a space whereby I needed to uphold the community standards of research, and in this instance, I experienced an intersection of identities.

At one point I wrote in my personal journal I supported the resignation suggestion. But I began to think of the consequences of a physical distancing away from the values of the Centre. Knowing no way to break the deadlock that was evolving. and feeling little choice in the matter, I conceded to the parameters set by my academic co-investigator. I included my board resignation as part of my ethics submission to the university for research involving human participants. I presented the Chair of the Board and the Executive Director a resignation letter. At that time, they both suggested I submit the letter to the Board in person in October , which was two months away. My ethical submission indicates my support of the need to resign, but by agreeing to wait several months, until the Board met, was also an indicator of resistance. My action appeased demands from the academic co-investigator, and from the community co-investigator, but there was really no resolution to the problem.

Below is an excerpt from part of my ethics submission.

> EXCERPT 18
> (Conflict of Interests: Section of Ethics Submission, August 2004)
>
> This research study is a collaborative effort that intends to build partnerships between the academic and disability communities and lay the groundwork for partnerships with government and potential employers. The Primary Investigator is a graduate student enrolled in the university. She is also a member of the Centre, serves on numerous committees and holds a seat on the Board of Directors. This community involvement will be an asset to building partnerships and gaining access to do the research.
>
> To avoid any perceived conflict of interest the Primary Investigator has resigned from the Board in anticipation of ethics approval to proceed with the study. The Primary Investigator will be available to provide updates and answer general questions about the study on a quarterly basis or upon request of the Board. Updates or any such presentation will be general and will not address specific and/or confidential materials covered by participants within focus group sessions, or other methods of data collection. (Appendix B)

There is a paradox at play in this situation. Without being a woman with a disability actively involved in the disability community I am reasonably sure I not would have had community support to begin this research. In Chapter 4, the guiding principles for research involving individuals with disabilities are listed (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). One point from this list is that direct involvement of people with disabilities, in the research process, facilitates a more accurate, and authentic, analysis. In this case, it was the Board position that confirmed to funding agencies my active, and recent involvement with the Centre. The academic co-investigator suggested my social location as a woman with a disability was also an indicator of involvement, but here I must disagree. Many people have disabilities, but not everyone is an active participant in the disability community.

The introductory quote by Monika Morris, "whoever gets to do the research drives the definition of what research is and how it is used," is a rather an ironic statement to describe PAR (2002, p. 9). However, it does set the tone for the importance of research of this nature to be driven by people who have disabilities, because it is their voice that is being presented. Knowing that research stems from the university, and that values are constructed from historically constituted knowledges and practices. which have little empathy for issues of disability oppression, I was worried about whose voice would prevail.

Claire Tregaskis (2004) writes of the conflict she experienced as a researcher with a disability doing PAR within the disability community. She too speaks of the added intensity a researcher with a disability may experience and writes that, "perhaps then, disabled persons experience is indicative of a more general concern within the research community at being torn between the academic and fund-holder demands associated with research process, and a personal desire for accountability toward groups and individuals with whom research is conducted" (p. 129). Tregaskis very much describe my perspective.

However, understanding my perspective did not make competing constituencies easier to deal with. I discussed my perspective in an academic environment but the advice was consistent. (PJE Oct, 14, 2004).

> EXCERPT 19
> (Personal Journal Entry, October 14, 2004)
>
> Must offer resignation. Leave is not acceptable.

I tendered my Board resignation at the first meeting of the year.

> EXCERPT 20
> (Michelle's partial resignation letter to the Board, submitted October 14, 2004)
>
> I am very excited to have the opportunity to bring disability issues into the thoughts of the university researchers. My hope is that positive experiences will be encountered between the study participants, the Centre and the university.
>
> The problem I have at the present is rather ironic. I feel we received this grant because of the community connection. However, part of the research ethics mandate is for the researcher (me) not to be in any type of perceived conflict, which includes holding a position or perceived position of power, such as a Board of Directors position. Because of this, university researchers informed me that I must resign my position from the Board effective immediately. It is with great sadness that I will do so. I will be glad to answer any questions the Board may have regarded the research study. I can arrange a more formal presentation if it is so desired. I am also available to update the Board on study progress either as the Board sees fit or during scheduled intervals.

I was not neutral in my approach. van Dijk writes that, "there cannot be aloof, let alone a neutral, position of critical scholars" (1993. p. 5 of 36). Space between competing constituencies is not a comfortable space. The community investigator remarked to me she felt she was in a David and Goliath relationship. I informed the academic co-investigator about this tension in an e-mail.

> EXCERPT 21
> (E-mail: From Michelle to academic co-investigator, October 14, 2004)
>
> I reconfirmed my resignation with the Centre. The question posed to me was why is it so essential I am not associated with the Centre and I am still permitted to maintain my funded relationship with the university. I inform you of this just so you are aware what community has expressed to me. I am not so sure it is that my presence is so valued or if it is a David & Goliath type issue.

I received the following reply from the academic co-investigator:

> EXCERPT 22
> (Reply From the Academic co-investigator to Michelle, October, 14, 2004)
>
> There is a difference between your relationship to the university, your relationship to the Centre and your new relationship to the Centre and your participants while doing this project. The issue is around power, who holds it, which direction it's flowing, who benefits from its exercise, and who is in potential harm if that power is abused.
>
> I'm having some difficulty understanding how these various relationships are being construed by Centre … . Perhaps it is the insistence that those in the Centre are not a "vulnerable" population who needs to be protected and can operate on par with any other institution. I'm not sure.
>
> And if that is the case then I agree that the Centre could be accorded equal agency to act.

In excerpt 22, the academic co-investigator expresses confusion about what is taking place. She strives to place my relationship, with the Centre, into a new researcher configuration in an effort to maintain ethical standards.

My role within the university was that I was a graduate student receiving a graduate assistantship. Taking on the label of a researcher within this environment necessitated acknowledgment, and respect, for the rules and regulations that governs the university structure. The role of student requires me to work within the boundaries of a hierarchical system, in which, the opinion of the student is generally located at the bottom (van Dijk, 1993). Within this environment, I was unsure disability issues would be heard.

My role as a Board member was that I was one of fifteen individuals making decisions that focused on maintaining the philosophy of the Centre. Day to day decision making is the role of the Executive Director. One basic premise of the Independent Living philosophy (Chapter 1) is to construct new opportunities for people with disabilities, so that they can gain access to full citizenship within society. As discussed in Chapter 1, the Independent Living philosophy strives to achieve systems from which individuals become self-sufficient, and speak for her/him self ,rather than have it inaccurately done by a third person expert. Because the research took place within an organization flourishing on self-determination and the power of voice, I was unable to envision how I could justify a recommendation originating within the university, through the academic co-investigator, that directly impacted an intimate part of the organization.

Differing opinions prevailed about whether my Board position was or was not appropriate. My point throughout all discussion was that I did not want to be perceived as a researcher from the university, who made decisions about who should or should not be on the Board of the Centre. From my perspective, this approach, without group discussion between the research team and the Board, reinforces the discourse of experts' theory (Stanley & Wise, 1983). Differing values, and perspectives, restrict people with disabilities from feeling their expertise is acknowledged, and this inhibits a shared sense of partnership (Krogh, 1998). I felt there was resistance within the research team to acknowledge the expertise of the Board and their ability to deal with my dual role.

Needing to demonstrate community involvement and the academic advice of being impartial confirms the post structural construct of subjectivity as a site of conflicting forms (Weedon, 1997). This meaning that, discursive interpretations can reconfigure a person to be many representations at once. The conflict created here is between the community vision of who constitutes a person they want reflecting lived experience and the academic vision of what constitutes a good researcher.

> EXCERPT 23
> (Reply From the Academic Co-investigator, October 14, 2004; Continued)
>
> However, we are dealing here with the [ethical committee] where the issue of who is vulnerable and who is powerful is more entrenched. You may want to journal about this important aspect of negotiating access in PAR and differing views about power and agency.

The university is obligated to work within external parameters that uphold certain ethical standards. Historically, external cognitive authority has dominated, categorized, and organized people with disabilities. In Chapter 3, I wrote of a "bio-energetic shrinking" which confirms people with disabilities are less than others in society (Charlton, 1998, p. 7). And of writers and who address the difficulty it is for others who do not have disabilities to fully understand what it is like to live within this type of oppression (Wendell, 1996; Silvers, 1994). Living in a disabled body and/or mind makes one very familiar with cognitive authority, bio-energetic shrinking, and the sense there is only one way to achieve the means. Taking PAR as an example of how to mitigate authority in partnership, one has to question if it is an achievable ideal. In this situation the academic co-investigator believed she was justified telling me to resign from the Board. Deconstructing traditional approaches to research and shedding the logic approach is difficult in an environment steeped in protocol.

In an effort to neutralize positions of power (researcher on the Board) the academic co-investigator believed the Ethics Review Committee, to avoid potential conflict, would request that I vacate the position. This potential act of protection from within the university suggests the disability organization is unable to protect itself. Void of other discussion within the Centre my resignation was perceived as a directive for the Centre from the university. It was inconsequential to the Centre and its Board why the directive was issued. I say this not because the Centre does not uphold ethical standards, but because the Board was unable to configure my position on the Board as an ethical issue.

I read my letter of resignation to the Board and prepared to leave the meeting.

> EXCERPT 24
> (E-mail: From Michelle to Academic co-investigator and independent academic advisor, October, 14, 2004)
>
> I presented to the Board of the Centre tonight. All did not go as planned.
>
> There were major problems (without co-investigator's presence) about my resignation. I will discuss it further when I have had to sort this out in my mind.
>
> How could I have taken a different approach when I had not anticipated such an uprising?

The next day I wrote:

> EXCERPT 25
> (Michelle, Journal Entry October, 15, 2004)
>
> Initially a good response to the study. A lot of questions about PAR, how the process works. At the end of my presentation I confirmed the need for my resignation and what an uproar. .... They felt the 'university' was "dictating" to them who could and could not be on a Board.

When I submitted my resignation to the board I anticipated some reaction but I was quite unprepared for the passionate backlash. The Board contextualized my position (on the Board) as one voice of many, no more or less important than any other. I think the Board members construed my resignation as my personal acknowledgment of accepting university interpretations of how to do good research. I gathered from conversation that night that the Board interpreted community/Board involvement not as a liability but as an insurance to accurately project the voices of women with disabilities. Similar to university research standards this ensured a community standard. The members of the Board were unwilling to support my resignation.

A person within the university asked me if *I* guided the Board into developing particular ideals around the Ethics submission. This was certainly not my intent and I would argue this was not the case. Board members make choices based on their beliefs and group discussion. The directive from the co-investigator to leave the Board stemmed from research practice and ethical concerns for so-called vulnerable populations and power imbalances. Failure to consider the Board perspective as playing a role in the partnership and decision making process, resulted in conflict.

When I went home that night, I gave in my resignation I sought advice through e-mail from the academic co-investigator and an independent advisor at the university who were familiar with the project. One person responded:

> EXCERPT 26
> (E-mail: From an independent advisor to Michelle, October 15, 2004)
>
> My sense is that you might continue on the Board, documenting any conflict of interest or issues of power that arise (including the discussion that ensued the other evening). An explicit discussion of issues of power is planned as part of your research anyway. There you can lay these circumstances on the table as part of a full exploration of power and how it emerges, circulates, etc. ... If this resignation becomes more of an issue than remaining, it does become counterproductive, doesn't it.

It was a relief that the issue was resolved but I did wonder at the time why it had to reach the point of confrontation with the Board. Dominance is seldom total (van Dijk, 1993). This excerpt demonstrates how the issue was unbendable while I was phrasing the problem but when others began to voice objections a counter power evolved which deconstructed the importance of the resignation.

The Board rejected my resignation.

> EXCEPT 27
> (A partial personal letter to Michelle from the Board, Nov 1, 2004)
>
> Dear Michelle:
> Further to concerns voiced regarding your continued participation as a board member while engaging in the XXX research project:
>
> Recap: On October 14, 2004, Ms Michelle Murdoch tendered her resignation to the Board of Directors. Ms Murdoch indicated at this time that it had been expressed to her, that there could be a conflict of interest based on her board involvement and the perceived power position she would hold as a board member by individuals participating in focus groups

> with the research project. Ms Murdoch left the meeting and the board proceeded to discuss the implications of her resignation.
>
> It was felt that in view of Ms Murdoch's commitment to the Independent Living movement and her long-standing support of the Centre as a volunteer and as an elected member of our Board of Directors, and further, as someone who has been instrumental in bringing about change in a way that is empowering for all involved, by challenging, guiding and supporting the work of Centre staff and volunteers, that her leadership should continue.

The problems of historical representation of disability and the ways in which dominant discourse reiterates such representation carry the complexity of the issue beyond 'my' resignation. "Subtle social closure mechanisms can be operative in partnerships which resist the dominant rhetoric of participation" (Boyce 1998, p. 89). Chapter 4, spoke of issues within partnership, avoiding a sense of the university rescue missions (Visweswaran, 1994) and the value of claiming ownership (Mc Taggart, 1997). It seems the Board blocked dominant rhetoric and gained ownership by rejecting my resignation letter.

> EXCERPT 28
> (Personal letter to Michelle from the Board, Nov 1, 2004; continued)
>
> Michelle, adhering to the tenets of Independent Living and in particular the principles of the Centre, the Board of Directors declines to accept your resignation based on a perceived conflict of interest. The philosophy of Independent Living clearly adheres to the rights of all individuals to participate fully in choices that affect their lives. No individual has power or influence over another person. It was felt that based on this philosophy as well as the principles of the Centre that acceptance of you resignation would be a contravention of these principles.

The ideal "no one should have power over another" (excerpt 28) symbolizes the Board's involvement in the Independent Living resistance movement. Traditionally some researchers have used the personal experiences of people with disabilities to support professional interests rather than participant empowerment (Meister, 2003; Marks, 1999). Historical relationships with researchers combined with a structured resistance movement that supports people with disabilities away from various types of systemic forms of power encourages resistance to dominant discourse on many levels. While Chapter 3, stressed the difficulty of overcoming domination the Board reaction indicates such a process can and does happen.

The Independent Living perspective very much influenced the Board decision to rescind my resignation. In doing so the Board exerted power over me and disregarded either my intent or spoke for me. I am not sure which, but I do think it critical to suggest the Board position was not about me as an individual but rather about resistance to issues that affected the Centre.I say this because abiding by the recommendation in the submission, given by the academic co-investigator, suggested the disability community does not have and cannot exercise power.

> EXCERPT 29
> (Partial personal letter to Michelle from the Board, Nov 1, 2004; continued)
>
> Mission Statement
> The Centre is a consumer-controlled organization committed to providing supports, resources and opportunities for empowerment, which enable persons with disabilities to make informed choices about their lives.
>
> The Board is prepared to have you excuse yourself from discussions involving the project at board meetings as you are the primary researcher involved in the initiative but are unwilling to accept your resignation based on perceptions of external agencies or organizations who may not fully understand our philosophy.
>
> The philosophy of Independent Living clearly adheres to the rights of all individuals to participate fully in choices that affect their lives. No

> individual has power or influence over another person. It was felt that based on this philosophy as well as the principles of the Centre that acceptance of you resignation would be a contravention of these principles.

Excerpt 29, demonstrates how the board deconstructs traditional authority. I was unsuccessful, in part because of my low status as a student, articulating the community perspective to the academic co-investigator who supported the ethical submission. Addressing issues of power, van Dijk writes, “lack of power is measured by its lack of active or controlled access to discourse” (1993, p. 8 of 36). Giving the Board a concrete issue on which to challenge the Ethic’s submission allowed right of entry into direct communication. Perhaps Cooke and Kothari (2001) would call the Board action tyranny of the group, but I feel the action reestablished the notion that boundaries must be and should be negotiated rather than commanded through traditional approaches to what constitutes good research. It is more optimal if such negotiation takes place before conflict arises.

Circumvention of power entails full inclusion of all collaborators within the conversation (Kesby, 2005). It is imperative that partnerships consider the impact of disability oppression acknowledging that it is difficult to articulate. Full partnership demands inclusion in discussions involving research policy and standards as well as flexibility of interpretation of policy and standards. Understanding the other persons point of view contributes to a sense of partnership. Establishing a space that supports difference, through the deconstruction of social and cultural normatives is an essential part of disability feminism (Chapter 2). I sometimes think I did not uphold my knowledge of disability theory when I resigned from the Board. There were layers of power and authority that influenced my behaviour, but ultimately feel I chose a passive route.

One way to manage issues of power within partnerships is to have an independent review throughout the community-based research project. Khanlou & Peter claim an independent review would "ensure ethical and scientific standards are met" (2005, p. 2337). Research can retain a scholarly approach without the approach being so rigid that collaborators or participants feel undermined by the process. Ultimately all collaborators could potentially benefit from an independent review structure. The challenge would be to devise a structure that would identify partnership risk, devise plans to minimize the risk, uphold standards of partners, appear impartial and commit time in planning. There would be no gain if such a structure reiterates dominant discourse. It is essential that the ground work is in place so that the community does not feel the university is a hegemonic presence within partnership.

In conclusion collaboration implies a contribution of at least two parties (Lord & Church, 1998). In this case unexpected involvement of Board of Directors of the Centre demonstrated how academic-community research has significant outreach beyond the anticipated collaborators. The Board's sense of exclusion within this process resulted in the letter of refusal to accept my resignation. The theoretical construction of PAR encourages decisions that fully engage all collaborators. If the university and community perceive a value to participatory approaches to community-academic research changes are critical.

I had brought the university research policy to the attention of the community co-investigator thinking she might better understand why my ethical submission was structured as it was. The result was that some of the wording within the policy we examined resulted in further disengagement of the community co-investigator in the ethical submission. For this reason I have purposively selected three policies for critical discourse analysis. These polices include:

1. Inclusion in Research
2. Respect for Justice and Inclusiveness
3. Respect for Vulnerable Persons

6.2 Varying Interpretation of University Research Policy

Historically, best practices for doing research originate from universities (Khanlou & Peter, 2005). Policy and procedure regulate practices. Best practices as portrayed in policy must be flexible to meet the needs of a wide variety of researchers. In an effort to maintain high standards and to account for difference within faculties the university has created research policies.

> EXCERPT 30
> (Policy: Inclusion in Research)
>
> An important aspect of the principle of justice is the fair distribution of benefits and burdens. Members of society should neither bear an unfair share of the direct burdens of participating in research, nor should they be unfairly excluded from potential benefits of research participation

This policy addresses the necessity of fairness within research. It does not deal with differences in perspective. For example, a researcher intends to select participants in a manner that would best suit the need for diversity within the project; a common practice not generally considered exclusionary or unfair.

A sense of inclusion and exclusion depends on one's life experiences. Traditionally, living with disabilities means identification by type of disability (physical and/or mental), categorization according to disability, and social stigmatization whereby because of their disability they can be less desirable than criminals (Chapter 3). Disability is about the body and/or the mind determined as different due to the prevalence of stigmatizing social/cultural normatives, the social stigma of difference, and rejection of difference. From Chapter 3, it becomes apparent living within a world as a *deficit* makes one very aware exclusion is a way of life for some marginalized people (Hughes, 2005). Exclusion may speak to lack of physical access, lack of access to traditional forms of communication or the stigmatization of mental illness. When life is dominated by exclusionary practices, words such as *unfair* and exclusion (Excerpt 30) are difficult to contextualize. Differences in how individuals with disability are portrayed in text, socially and culturally (Chapter 3) make it obvious that the normative for 'fair' to a person with a disability is likely different from the normative for 'fair' to a person without a disability.

It is not clear in the policy whose standards determine the meaning attached to such words. A researcher should anticipate but not presume that varying partners may attach different ideologies to some words. In this case ideologies constructed within the resistance movement that structures the Independent Living philosophy create a particular discourse around contentious words such as unfair and exclusion (Excerpt 30). Conversation that enabled a diverse interpretation of contentious words may have diminished some areas of conflict found throughout this case.

There is a justice research policy that states:

> EXCERPT 31
> (Policy: Respect for Justice and Inclusiveness)
>
> Justice connotes fairness and equity. Procedural justice requires that the ethics review process have fair methods, standards and procedures for reviewing research proposals, and that the process be effectively independent. Justice also concerns the distribution of benefits and burdens of research. On the one hand, distributive justice means that no segment of the population should be unfairly burdened with the harms of research. It thus imposes particular obligations toward individuals who are vulnerable and unable to protect their own interests in order to ensure that they are not exploited for the advancement of knowledge. On the other hand, distributive justice also imposes duties neither to neglect nor discriminate against individuals and groups who may benefit from advances in research.

Determining unfair policy and deciding who does or does not benefit from research requires subjective interpretation. Rarely do informed people oppressed by particular discourse have opportunity to influence the standards (Holmes, 2004). As discussed in Chapter 2, the notion of fairness, often serves to support dominant interpretations. One example articulated in Chapter 3, demonstrates how white feminists were seeking a voice and rights for all women, while Black women were in the houses of these women as cheap labourers. The problem is that it is difficult to understand the context of fairness and unfairness outside of our individual limited perspectives.

There are infinite arguments about what constitutes a vulnerable person. Through policy, the Ethical Review Committee sets standards and determines specific social designations as vulnerable. From this policy evolved the need to examine the university definition for “individuals who are vulnerable.”

> EXCERPT 32
> (Policy: Respect for Vulnerable Persons)
>
> Respect for human dignity entails high ethical obligations towards vulnerable persons - to those whose temporary or permanent lack of competence and/or decision-making capacity make them vulnerable. Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination. Ethical obligations to vulnerable persons involved in research will require special procedures to protect their interests (Ethics Policy 3).

Discourse is effective producing stereotypes. van Dijk (1993) writes, “one of the most conspicuous forms of over completeness in discourse is the irrelevant negative categorizations of participants in order to delegitimize or marginalize their opinions or actions” (p. 35 of 47). Such attitudes toward people with disabilities are why Balcazar, Keys, Kaplan, and Suarez-Balcazar (1998) specifically articulated principles to guide research involving disability oppression (Chapter 4). Discourses that maintain people with disabilities as less than, or ‘Other,’ are deeply embedded, subtle and at times obvious.

Disability is often fluid in nature. Over a life span one may have fluctuations of wellness and fluctuations’ poor health. Within the Centre there are consumers who, at times, choose to live in institutions so that they have their physical needs met. (I do not have the knowledge to address mental health experiences). Living within an institution may reflect long-term or prolonged periods of transient stays as institutionalization need not always be permanent. Such individuals may work or may volunteer in various sectors of society yet because of where they live, when examined with the lens of this policy, are deemed vulnerable by the university.

My interpretation of this tells me this policy encourages dominant discourse because it stereotypes all individuals living in institutions as vulnerable. If one lives in an institution, for whatever reason, you are less capable of making a decision. Such policy holds the potential to legitimize this patriarchal type of social attitude. My personal life experiences tell me this policy is discriminatory. I spent months in an institution with the same mind then as I have now. Because my physical needs were deemed medically considerable, my family (note: not me) was asked to consider (my) long-term institutionalization. Presumed vulnerability due to institutionalization reiterates a negative connotation of institutionalization by choice; perhaps an odd statement from a disability activist. But some people do select to have their physical needs met by living in an institution. This choice should not reflect a presumption of vulnerability.

I have been asked if using my own example is manipulating the term vulnerable into a relative term. How is one to know what is relative? I think providing a blanket statement of who is or is not vulnerable because of where they reside is an excellent example of cognitive authority and the power of dominant discourses to construct determinations about others (Wendell, 1996). What is missing, from my perspective is that vulnerability is not portrayed as relational to intent, but rather as relational to where one resides.

My presumption was that if conflict arose within the research partnership I could take the problem back to the university Ethical Review Committee. However, the community co-investigator informed me she had a problem with such an approach. Taking the Board issue (as one example) back to the university Ethical Review Committee, she suggested, was counter productive. It would require that the team return back to the structure that formulated the discourse that the produced the problem. Such an approach held potential to bypass all community voice in favour of only the academic perspective. Bringing the issue to the Board disregarded university venues of resolution. Van Dijk (1993) states perspectives of those in power is not the concern of a critical scholar. She writes, "critical scholars should not worry about the interests or perspectives of those in power, who are best placed to take care of their own interests anyway" (p. 5 of 36).

PAR calls for a reconfiguration of our approaches to research. In this case the ethical submission was interpreted as a university-based task. In fact waiting for an ethical approval before starting to build community capacity (with university and community) is the antithesis of the philosophy of participatory approaches (Khanlou & Peter, 2005). Khanlou & Peter state the problem, "it would be antithetical to PAR principles for PAR researchers to propose methods before having the involvement of community interests. Yet, ethics approval must be sought before the research begins and generally, barring any major change in procedure, it is often sought only once, at the beginning of the research"

(p. 2337). The basic philosophy of PAR seems to conflict here with the principles of research within the university and the funding agency.

In summary, participatory approaches to research involving partnerships that include marginalized women are complex and come with no easy solutions. It is beneficial for the researcher to anticipate those issues of difference and representation that can challenge the notion of equity within PAR.

6.3 Summary

Feminist case study is an approach to research that enables examination of social phenomena through an individual case rather than as a comparative analysis (Reinharz, 1992; Padula & Miller, 1999). Evidence presented through an individual case approach suggesting differing ideologies within a partnership may result in elements of conflict.

Feminist critical discourse analysis is an intricate multi disciplinary method of research that examines paradigms of power and social injustices through the application of fundamental values of feminist methodology (Lazar, 2004). Through critical discourse analysis of the evidence an understanding as to the origins of the conflict begins to emerge.

This feminist post structuralist approach does not seek truths but rather strives to disrupt dominant knowledges (Gavey, 1989, p. p. 463). The process of revealing dominant discourse found within the politics of partnership exposes how issues of difference and representation influence the process of participatory action research.

The final chapter, 7, summarizes this reflective analysis.

CHAPTER 7

Conclusion

> Accepting the validity of other people's beliefs, feelings and behaviours doesn't mean that we have either to share them or see them as preferential- just different (Stanley & Wise, 1993, p. 22).

Reflection back over my primary research evoked a wide variety of personal response. Leaving the participatory action research (PAR) experience with a variety of contradictory and often unexplained emotions was difficult. I was bothered by the way some events unraveled, most of which have been revealed within this thesis. This personal discomfort conflicted with the recognition received by the project and the acknowledgment of an award by a national organization and a distinguished researcher. In chapter I, I wrote, "being a primary investigator in a participatory action research (PAR) was the highlight of my graduate studies." For quite sometime following the completion of the research project, I felt as if I was a spoiled child, who refused to be satisfied. It was not until now that these feelings have dissipated.

Acknowledging divergence in beliefs, as suggested by Stanley and Wise (1993) symbolizes a respect for difference and an acceptance for varying ways of knowing. Issues of power, difference, and representation within one partnership have been critically examined throughout this thesis. Key to this analysis is that it upholds feminist values by critically examining feminist research methods and ways of knowing (Oakley, 2000). This thesis reflected back on academic ideals that define good research practices and how these ideologies can conflict with community perspectives about what makes research good.

The distinction between the thesis and the research reports is that each serves a different purpose. The PAR was group work that concentrated on issues identified and discussed by participants. This thesis represents the perspective and the work of one individual. The value of such a contribution is that it enables conversation about how issues of difference and representation influenced the research process.

7.1 Change

Schratz and Walker (1995) write that it is essential to reflect back on the research process without falling into infinite regression. Feminist research is focused on generating change (Reinharz, 1992). Therefore, the process of critical reflection appears most efficient when directly linked to the process of change.

Change happens in one of three ways (Gatenby & Humphries, 2000):

1. From a feminist perspective, change may occur when women are involved in the research process, so that they directly influence others to rethink their ways of doing.
2. Change may occur when the research process is demystified, meaning all stakeholders are aware of the process, and political consequences.

3. And research may evoke change in the researcher through self-reflexivity. For some this change is exciting, for others it is painful, and yet others may locate themselves somewhere in the middle.

7.1.1 Change and Inclusion

Change may occur when women are involved in the research process so that they directly influence others to rethink their ways of doing (Gatenby & Humphries, 2000). Chapter 5, presented two problems with the research recruitment process (Appendix A). Participant recruitment design was hierarchical, because researchers were initially granted authority to chose which participants would or would not take part in the research project. In Chapter 4, PAR was described as a grass roots strand of action research that continues of the process of knowledge production as encouraged by Paulo Freire (Noffke & Somekh, 2005). Grass roots refers to a bottom up approach wherein power is dislocated from the top of the hierarchical structure and redirected to those who traditionally locate space at the bottom. Researchers, selecting a participant from a submitted application form, is not an example of the grass roots approach.

Therefore, purposive selection offered potential for researchers to reiterate dominant discourse about disability. As discussed in chapter 3, representation, "refers to the body of shared understandings that constitute the medium through which individuals engage in transactions with one another, with the world they share, and themselves" (Sorrell 2004, p. 159). When applied to disability, shared understandings may be desired or undesired but characteristically not in the control of those being represented. Purposive selection offered the potential for women to feel discriminated against because of their disability. This is a theoretical discussion of perceived risk because the participant recruitment process was changed once this potential was realized.

Lather (1988) writes that one purpose of feminist research is to empower the researched and contribute to the generation of change enhancing social research. Participant involvement in the recruitment process was empowering to some women within the disability community who were interested in research. The revised recruitment process enabled all women with disabilities , within a predetermined designated geographical area, opportunity to participate. Khanlou and Peter (2005) write that, "within particular communities issues can also arise with respect to the fair selection of participants. Interested members of the community should be given meaningful opportunities to participate, especially if they have been under represented in the past" (p. 2336). Thus, the inclusionary process responded to the flaws in my initial approach to participant selection, avoiding the perception that one's type of disability was a determining factor to participant selection. I think, response to participant concern early in the selection process enhanced the women's sense of ownership within the project.

Part of the inclusionary process necessitates a sense of ownership within the research. As discussed in chapter 4, "authentic participation in research means sharing in the way research is conceptualized, practiced, and brought to bear on the life-world. It means ownership, that is, responsible agency in the production of knowledge and improvement in practice" (McTaggart, 1997, p.28). Creating a sense of ownership amongst all individuals, was paramount, and happened in numerous ways beyond the recruitment phase. For example, the participants and the co-investigators edited report drafts. Each contributed their revisions and recommendations for change. All requests for report drafts and final reports were available in Braille, text and electronic formats.

As front line workers, the research assistant and I were very aware of the necessity of flexibility. For example, one participant missed the 5-hour focus group session because of a family death. She requested an interview in place of the missed session. At her convenience I visited her home and conducted a personal interview. There was another participant who missed a session but she declined opportunity for a personal interview. The research assistant and I worked together to respond to the multiplicity of needs and diversity of ways of doing as our goal was to create an inclusive research environment. We spoke frequently to everyone about working together as a group and ways to become more engaged in the initiative, noting levels of participant engagement varied.

Pain & Francis claim that, "the defining characteristic of participatory research is not so much the methods and techniques employed but the degree of engagement of participants within and beyond the research encounter" (2003, p. 46). There were barriers that prevented complete engagement of participants and/or sectors of the disability community. By this I mean, in an ideal world I could envision a very different type of participant involvement. For example, prior to any proposal submission I envision gathering a large focus group of women with disabilities to debate possible research topics.

This gathering would involve paying for transportation, accommodating diversity of communication, such as sign language interpreters, and paying for incidentals that arise with such a meeting. This approach offers potential to extinguish lines of distinction between researchers and participants. One barrier to this approach is that neither the Centre nor the university could financially support endeavors that would *possibly* result in a research project. In this case the ideal of including a broad base of women in preliminary stages of research design was not fiscally possible at the time.

The approach taken throughout the PAR demonstrates (to some degree) the feminist value of an inclusive research process. But barriers still exist that inhibit the provision of space for historically silenced voices. Some of these barriers include lack of funds to include more women into the discussion. The small research grant enabled a gathering of women to take part in research, but not to the extent desired by participants and some others on the research team. And despite good intention traditional approaches to participant selection offered potential to exclude some women. These are examples of the complexity of research designed to locate historically silent voices and the realities of practice.

7.1.2 Demystifying the Research Process

Change may occur when the research process is demystified, meaning all stakeholders are aware of the process and political consequences (Gatenby & Humphries, 2000, p. 90). Becoming aware of process and political consequences is difficult when stakeholders or constituents interpret process and political consequences through a diversity of perspectives. For example, choosing to have the research funds controlled by the Centre was one step towards encouraging empowerment, and enabling community control. However, it is difficult to determine now, had we known we would not have had access to the university print services, if we would have made the same choice, as the impact of our choice was not fully revealed until the end of the project.

When an area of study has been ignored, deconstructing power and authority is particularly complex. This is because it is difficult to work in an area whereby few, if any, templates of understanding about power, as it relates to the impaired body or mind, have been developed (Garland-Thomson, 2002; Wendell, 1997). The problem with understanding the lived experience, within the unspoken confines of post structuralism, is that the notion of creating an authentic voice appears unachievable, because such meanings are interpretations of socially constructed language.

The lack of templates, and understanding the lived experiences of women with disabilities, were key challenges within the PAR. Lather (1988) writes the way one looks at the world is inherently bound to socio-cultural influences and lived experiences. Try as we may to identify with marginalized groups, it is difficult to develop a full understanding of perspective if one has not had similar experiences. With that said marginalized groups are also not homogenous. For example, while I am a woman with specific disabilities, I am not intimately familiar with mental health issues. Thus, there are layers of difference within the one oppression which contributes to the complexity of working with marginalized people. Becoming aware of the process, and the political consequence, as suggested by Gatenby & Humphries (2000), happens on many levels and at varying times. This awareness must happen not only with participants but also with the researchers.

Paramount in this case study was the incident involving the Board resignation (Chapter 6). Very early in the partnership, I was aware my Board involvement could cause conflict. The community co-investigator was firm about her position, she stated my placement on the Board was not a point of conflict. The academic co-investigator did not share this perspective. She believed the position did offer potential for conflict. I did not predict the passionate response of the Board, but, on retrospect, their reaction makes sense. McTaggart (1998) states bringing together of groups inevitably involves differences; such as in disparity in power, status, influence, and/or language. The Board interpreted concern for ethical standards to be more indicative of academic gatekeeping. Therefore, the board resisted the established authority of the ethical submission, and constructed its own ethical boundaries.

One could take an optimistic view on this incident, and suggest, in the end, the Board did negotiate a response that was in their favour. The ethical submission in the PAR, I believe was viewed by the community co-investigator, as university protocol. Frank discussion about who benefits from strong ethical approaches, respect for differing points of view, and a desire of all parties to produce effective, and respectful resolutions to contentious issues is fundamental. I think demystification would be more effective if this negotiation had taken place earlier in the research process.

The Centre represents the marginalized voices of women, men and children with disabilities. In this sense the Centre, enabled the university, through its researchers, access to some of the women it serves. But the Centre resisted on many fronts what Visweswaran calls the "university rescue mission in search of the voiceless" (1994, p. 69). Demystifying and sharing power redirects the ethical submission away from a university rescue mission and into open conversation. A fresh approach may well involve more than one ethical submission and certainly considerably more time. If I were to take part in another research involving a partnership with a sector of the disability community I would develop relationships, create dialogue, and value differing opinions between researchers. I would also recommend that the the Board and/or the Executive committee become involved early in the process.

However, there are logistical problems to this inclusive approach. I wrote the ethical submission during the summer and the Board did not meet during the summer months. Therefore, increased Board involvement would have necessitated either the ethics submission to be delayed by several months, or the volunteer Board would have had to convene during the summer. Group consensus building is time-consuming, and time lines set out by the varying constituencies may challenge some or all of these ideals.

There are other levels on which one must demystify the research process. For example, very early one morning, months after the focus group sessions, I received a phone call. It was an excited participant wanting to know what book I read that formulated the research design. She was taking a course at the university that involved a project and for that project she wanted to use a participatory approach. We met over coffee and I informed her of some of the steps involved in the one research I was familiar with. I also said I was unable to find one how-to-do it book. In fact it was my experience that much of the literature I read circumvented specific methods used by the researchers. I interpreted my reading as having more of a theoretical and less of a practical perspective. It was mostly on retrospect that I began, and continue, to grasp a deeper meaning of the literature.

In summary demystifying the research process is a goal to strive for. It is important to recognize that the demystification process is fluid and happening from many different perspectives. Considering diversity of perspective, understanding the research method, acknowledging who holds the power, and pondering the impact of difference of philosophies, within partnerships, contributes to demystification.

7.1.3 Evoking Change through Self-Reflexivity

Research may evoke change in the researcher through self-reflexivity (Gatenby & Humphries, 2000). A reflective analysis generates insight gained by critically analyzing, and evaluating completed work (Hall & Hall, 1996). Mauthner and Doucet (1998) write that, "[r]eflexivity means reflecting upon and understanding our own personal, political and intellectual autobiographies as researchers making explicit where we are located in relation to our research respondents" (p. 121).

Reflexivity results in a deeper sense of understanding about complex issues. These deeper understandings are individually perspectival. Understanding that some words used within the university policy were perceived by the disability community as discriminatory, was self-revelatory. I had opportunity to inform the University of these perspectives, but I have no control over what the university will or will not do with the information. My focus has not been to attempt to change the working structure of the university. My concerns are directed towards the plight of women with disabilities.

PAR is a fluid approach to research that strives to address issues of social justice, social inclusion and exclusion, and the need for social change (Gatenby & Humphries, 2000; Morris, 2002). It focuses on participant involvement, raising the social consciousness by highlighting the value of the lived experience and making space for voices often omitted from dominant discourse (Kesby 2005; Hall, 2005). I entered the research apprehensive about how to induce social change, and how to achieve a sense of social justice. I leave it , still pondering its effect.

Some of the stories I heard from participants made me aware of my own position of privilege. Frequently, I thought of the words of Joan Meister (2003) a disability feminist, who questioned whether it not it was liberating to formally acknowledge the misery of the lives of many women with disabilities. For the most part, the research did not change the social milieu in which most participants survive. It did provide a venue through which they were offered voice and had control. Many of the women have since become friends, and keep in touch. The struggles have not changed, but rather we are now less isolated, or at least some of us, as we can share our stories and frustrations. Sometimes we make jokes using language, and ideals that are off bounds to those without disabilities because of impropriety. This is similar to other feminists who, over the years, have reclaimed words and granted them new meanings.

If a goal of feminist research is to empower the researched and contribute to the generation of change enhancing social research as suggested by Lather (1988) in a small way both the PAR, and this thesis, have achieved their feminist mandate. Since participating in the study, several of the participants have secured jobs, although most are underemployed. One participant, and the wonderful research assistant, have full time jobs at the Centre. Another participant has become the executive director of a provincial disability advocacy organization. In fact, more than half of the participants have increased their political awareness by joining the Board at the Centre, or other disability not-for-profit Boards. But all the while, each woman continues on with her daily struggle.

One of the community co-investigators has moved to central Canada where she continues to work in the field of disability social justice. The other community co-investigator and academic co-investigator continue on with their work. I have kept both informed of the content of this writing, and it is my hope they will understand the views I have presented here. I have since become Chair of the Board of the Centre. While my work as a disability activist continues, I also have a new position on a provincial feminist Board. My hope is that women with disabilities will increase participation in feminist environments. Another personal goal is to some day become involved with another PAR.

7.2 Conclusion

Throughout this thesis, use of practical examples that challenged authority, and power, within partnership illustrate the way theory and practice, through discussion, can stimulate a more effective praxis. The purpose of this critical discourse analysis was not to dispute the effectiveness of the primary project. My intent was to open the conversation around one case study and to examine on a broad level how issues of difference and representation influenced a PAR.

Theoretically, the academic conceptualizations of PAR imagine an equal distribution of power within partnerships. The fluidness of PAR, its grand scheme to circumvent power within the research process, and its call for a diversity of approaches that strive for social change, specifically in regards to marginalized people, makes it an intricate and complex approach to research. Because PAR is so fluid in design, predictions of power and the ways power relations play out, can be problematical. Participatory approaches necessitate a 'buy into' a philosophy that guides the overall research approach, strives for but does not automatically guarantee, higher standards that assure power equity.

Following the reflection process demanded from thesis writing, I have gained a sense of what PAR could be. Participatory approaches to research, while time consuming, challenging, and very much a personal commitment, offer the potential to transform research practices. I have heard, read, and understand the criticism that power equity is not attainable but I wonder if perhaps we readily take this view because the work involved in exploring alternatives is daunting. While I see the challenges to participatory approaches, I still wonder if some of these issues exist because we cannot shed embedded discourse that obstructs one's thinking to embrace research in a very different manner. It seems to me PAR is still in early design phases despite the fact it has been in use in a modified sense for fifty years.

One way to advance our understanding of participatory approaches is to open up the conversation, and talk about how PAR can become an even better process. What I have learned from this reflective analysis is that this research partnership involving women with disabilities, a disability organization, and the university, contained varying perspectives. Because of the diversity of perspective within the partnership and in differing power situations, issues of difference and representation did influence this participatory action research involving women with disabilities.

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APPENDIX A

Invitation and Information for Research Participants

*ALTERNATE FORMAT AVAILABLE.

Closing DATE for Applications: Nov 29, 2004

This is an invitation to participate in a research study. This study will bring together 10-12 women with disabilities who are interested in sharing their feelings, beliefs, about employment, education, and training in relation to Adaptive Technology (AT). AT is computer hardware and software that enables an individual with a disability to effectively use a computer. AT does not have to be technical; it may as simple as a height adjustable workstation.

My name is Michelle Murdoch and I am a woman with a disability. I volunteer at The Centre which provides services for people with disabilities. I am also a graduate student enrolled in the Women's Studies Masters Program. I would like to hear from women with different types of disabilities, of all ages, ethnicities, employment experiences, and skills using AT. If you are a woman who is currently working, seeking employment, attending a post secondary institution, or enrolled in a training program, please fill in the attached form or contact me directly. Contact information is below.

The research team will select 10 –12 participants from those who indicate their interest by completing the attached form. Not everyone who wants to participate can be included in this study because it is not practical to have a larger group given study objectives. Participant select will be as diverse as possible. Diverse refers to various kinds of disabilities, ages, work experience, and knowledge of Adaptive (or Assistive) Technology. No one will be discriminated against because of disability, race, or sexual orientation.

This study may benefit you by giving you an opportunity to:

1. Share your knowledge about disability, employment, unemployment, and AT with other women with disabilities.
2. Attend a workshop about AT.
3. Contribute to positive change by communicating shared experiences with government agencies, community organizations, and potential employers in St. John's and across Canada.

Selected participants will collectively decide what they want employers, educational institutions, and governments to know about women with disabilities, AT, employment or unemployment. All issues about how to gather, analyze, and communicate data will be discussed in the group before deciding how to proceed. Everyone's opinion is valuable and will be respected.

Tentatively, the plan is to join me in three 2-hour focus groups and one 2-hour AT workshop. Group meetings will take place at The Centre. These focus group meetings will be tape-recorded and/or recorded by a note-taker to ensure an accurate record of your comments and opinions. Participants will have an opportunity to read a copy of what they say (transcript) and may make changes, additions, and deletions to their own comments. The typist, my university supervisor, and I are the only other people who will read these transcripts. The audiotapes, notes, and transcripts will be kept in locked storage when not in use and will be destroyed seven years after completion of the project.

Participants will have the option of deciding whether they wish to remain anonymous. All participants will be required to keep confidential all discussions that take place during this study.

Participants will receive reimbursement for transportation to a maximum of $5.00 or each round trip. Participants who incur childcare expenses wile attending the focus groups and workshops will be reimbursed at $6.00/hr to a maximum of 8 hours. Alternate formatting costs will be provided for study participants. Accommodations such as attendant (helper) care will not be covered.

A summary report of the information gathered in this study will be shared by the ***Funder. Each participant will receive a copy of the final report. The report will also be distributed to governments, community organizations, and interested employers. A copy will be posted on Centre websites. Information gathered from this study may also be used in the preparation of scholarly papers or conference presentations.

If you have, any questions about this please contact:
Michelle Murdoch at ...
Academic co-investigator ...
Community co-investigator ...

The proposal for this research has been granted full approval by the by the Interdisciplinary Committee on Ethics in Human Research *** University. If you have ethical concerns about the research you may contact the Chairperson .... .

ALTERNATE FORMATS AVAILABLE

APPLICATION TO PARTICIPATE

PLEASE READ THE INFORMATION SHEET BEFORE COMPLETING THIS FORM.

****** ALTERNATE FORMATTING IS AVAILABLE UPON REQUEST.**

We are trying to bring together women of all ages with different types of disabilities, and varying work and education experiences. The following questions will help us in selecting a diverse group of participants. You do not have to answer any of these questions if you do not wish to.

When you have completed the form, please leave it in the envelope provided at the reception desk of the Centre, or email the information to me at the email address listed below. Alternate format accepted, just arrange through the Centre. Forms may also be mailed directly to the Centre. Please address the envelope Attention: Michelle Murdoch.

Yes, I am interested in participating in the research study called, ...

Name ____

Address ____

Contact Number ____________________ E-mail ____________

I identify my disability as

____

If I am selected, my preferred format of communication is:

____

My experience using Adaptive Technology is

____

____

____

This best describes my work experience at present: (check as many as apply)

☐ I am presently working
☐ I am attending a training program
☐ I am attending post secondary institution
☐ I am currently looking for work
☐ I have become discouraged in my effort to find work and am not currently looking for work
☐ Other (please describe)

I am in this age range (check one)

☐ 19-29 years
☐ 30-39 years
☐ 40-49 years
☐ 50-65 years

Please check one:

☐ I will require child care
☐ I will not require childcare

I have had the following types of jobs or education or training in the past five years. (Include any AT training you have had.)

____

____

____

THANK YOU FOR YOUR INTEREST

I will notify you if you are selected to participate in this study by (date TBA).
If you have, any questions about this study please contact:
Michelle Murdoch at ...
Academic co-investigator ...
Community co-investigator ...
Or leave a message in your desired format at .... Thank you.

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at *** University. If you have ethical concerns about the research you may contact the Chairperson of the *** ethics committee ....

CONSENT TO PARTICIPATE

Title of Study: Women with Disabilities and ....

Name of Participant: (please print) ______________________________

I understand that the study in which I am agreeing to participate involves sharing my feelings, beliefs, about employment, education, and training in relation to Adaptive Technology (AT). A group of 10-12 women with disabilities will meet for three 2-hour focus groups and one 2-hour AT workshop.

I know all information pertaining to this study can be made available in alternate formats. I must self-identify my need for an alternate format.

I understand participation in this study is voluntary. I may withdraw from the study at any time, regardless of the reason and without prejudice.

I understand that participants will work as a group deciding what we want others such as employers, educational institutions, and governments to know about women with disabilities, AT, employment or unemployment.

I understand I will have the option of deciding if and how I will be identified or if I want to remain anonymous.

I understand that I am under no obligation to answer any question that I do not wish to answer.

I understand that information sharing within the group will be recorded on audiotape and in handwritten notes.

I understand conversations between participants that occur during this study will be confidential and not discussed outside the group.

I understand I will be reimbursed for transportation to a maximum of $5.00 for each workshop or focus group meeting I attend.

I understand that childcare expenses I incur while attending the workshop or focus group meeting will be reimbursed at $6/hr to a maximum of 8 hours.

I understand all alternate formatting is available free of charge and upon request.

I understand I will not be reimbursed for other forms of accommodation such as attendant care that I incur while attending the workshop or focus group meetings.

I understand only Michelle … will have access to the original research study material.

I understand I will have an opportunity to review a copy of the audiotape transcript and notes taken during focus group meetings so that I can make changes, additions, and deletions to my own-recorded comments.

I understand I will have the opportunity to discuss and contribute to the analysis of study findings when the final draft is completed.

I understand that the information obtained from the focus groups and workshops and any other information sources deemed necessary by the participants will be used for the specified study and potential publication(s) arising from it. Information gathered from this study may also be used in the preparation of scholarly papers or conference presentations.

I understand all original data obtained from the focus groups, workshop, or other information sources identified by the participants will be shredded or erased at the end of seven years.

I understand …. (Funder) will receive a summary report of the information gathered in this study. This report will be distributed to governments, community organizations, and interested employers. A copy will be posted on the university and the Centre website.

Participant Signature: ______________________________
Date: ______________

I have explained as fully as I can the purpose and procedures of this study to the above volunteer. I have sought questions and I have answered any questions openly and honestly.

Researcher Signature: ______________________________
Date: __________________

Consent forms are available in alternate format. Please inform me of the format you prefer. You will be provided a copy of this form for your future reference.

If you have, any questions about this please contact:
Michelle Murdoch at …
Academic co-investigator …
Community co-investigator …
Or leave a message in your desired format at … . Thank you.
The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at *** University. If you have ethical concerns about the research you may contact the Chairperson of the *** ethics committee ….

APPENDIX B

Michelle Murdoch Aug. 16, 2004

INTERDISCIPLINARY COMMITTEE ON ETHICS IN HUMAN RESEARCH

ETHICS PROTOCOL

Topic: Women with Disabilities ....

1. Background, purpose, and justification

According to the Office of Disability Issues (ODI) (2002), half of all working-age Canadians with disabilities are unemployed. When data are broken down by gender, some sources report that 40-75% of women with disabilities are unemployed, underemployed or living below the poverty line (DisAbled Women's Network Canada, 2003; Masuda, 1998). The purpose of this study is to explore and document the experiences and perspectives of unemployed, underemployed and fully employed women with disabilities who report the need to use Adaptive Technology or AT within the workplace.

Access or accessibility refers to the ability of a person with a disability to fully use a service, technology, or building. The Roeher Institute talks about disability in terms of 'defending difference'. The Roeher Institute is a leading Canadian disability think tank that develops social policy recommendations about inclusion, citizenship, human rights, and equality for individuals with disabilities. "A central premise underlying democracy is the belief that people are different, to believe in rights is to believe in defending difference" (Roeher Institute, 2003).

This project will critically examine women's knowledge of, and experience with, computers and AT as tools for facilitating successful integration into the workplace. To achieve that end, this Participatory Action Research (PAR) project will bring together women with disabilities, community agencies, and academic researchers to explore the connections between gender, disability, employment, and underemployment and AT, and build capacity for effecting positive change.

One of the research partners is the Centre. The Centre is a consumer-controlled organization committed to providing supports, resources, and opportunities for empowerment, which enable persons with disabilities to make informed choices about their lives.

The four primary goals of this study are to:

> Create sustainable collaborative relationships between Centre, academics and potential employers to support transition into sustained employment for women with disabilities.
> Investigate how computers and adaptive technologies influence women's experiences of employment and seeking employment [and thus maintain or mitigate differences in employment rates in this population]
> Evaluate the value of the computer program at the Centre in meeting users needs for knowledge and information about AT.
> Identify mechanisms for sharing information about AT with other potential users.

The Principal Investigator (PI) of this proposed study is a woman with a disability who has extensive inside knowledge of the disability community. The disability community is a group of individuals who self-identify as having a physical or mental impairment. The word self-identify is used frequently within the disability community as it endorses the personal identification of need, as opposed to an institutional identification of need. Within this context, the word 'self-identify' reflects empowerment.

The Disability Rights Movement created a social model of disability that assumes that *all* persons with disabilities have a right to equal and full participation in society (Charlton, 1998, Enns & Neufeldt, 2003). This model identifies full citizenship within society by endorsing and promoting the importance of basic human rights. These rights are the right to choice, right to dignity of risk, right to make informed decisions, right to take responsibility, right to manage and control your own resources, right to find solutions that work for you, and the right to learn from each other (www....). The Centre embraces these rights in their Independent Living (IL) principles. This study will function with the understanding that IL principles will be applied at all times.

Few studies have been directed at exploring the connections between gender, disability, employment, and underemployment from the perspective of women with disabilities. This gap is capturing the attention of community agencies, academic researchers, and funding bodies. National disability organizations such as DisAbled Women's Network (DAWN) Canada endorse research about women with disabilities being done by individuals who have disabilities. When ethics approval is granted, this proposed study will be the first study of its kind funded by the ... (funding agency).

This study will use PAR because this methodology offers a wide range of approaches intended to build relationships with identified communities while ensuring some degree of reciprocity and social action with community members. (Suarez-Balcazar, Davis, Ferrari, Nyden, Olson, Alvarez, Molloy, & Toro 2004). PAR mandates a respectful and collaborative approach to planning, execution, and evaluation of results by participants.

DAWN Canada and the funding agency also promote collaborative, community-based research.

Because of the nature of PAR, data collection, analysis, and action plan are emergent and fluid processes. Experiential knowledge is brought to the research process when participants can articulate their issues and concerns, assist in development of materials, and participate in the process of facilitating change (Suarez-Balcazar et al., 2004, p. 106).

A central feature of the study is the seminar/workshop that will provide all participants with hands-on exposure to individuals who work in the field of and have extensive AT experience. At least one focus group meeting is planned before the workshop and up to focus group meetings after the workshop. At the first meeting, the PI and participants will decide on appropriate method of data collection. Possible options are questionnaires before and after the AT workshop, journaling, informal discussion, storytelling, or art expression.

Data collection and analysis will be an on-going process that ensures that data collected accurately reflects participants' meaning making at that moment in time and in that context. Transcripts of data collected in audiotapes and hand-written notes will be shared with study participants. At that time, participants will make any desired changes to the text that more closely reflect their beliefs and attitudes at the time. This is one way of ensuring valid findings. Participants may revise their own data only.

Participants will also participate in the data analysis and the development and dissemination of the final report. A draft of the preliminary analysis developed by the research team will be shared with participants for input suggestions from participants. Based on these suggestions, the research team will write a final draft of the report and circulate it to the study participants for final comments before dissemination.

The research team is planning to disseminate this study report. A written and/or adaptive format copy of the study report will be given to each participant, members of the research team and the funding agency . In addition, the research team will invite study participants to identify other suitable venues, agencies, and government departments for dissemination. Some of the intended venues are the Women's Studies website, the Division of Community Health website, national organizations such as Canadian Research Institute for the Advancement of Women (CRIAW), CCDS, DAWN Canada, the Neil Squire Foundation, Roeher Institute and other Centre's across Canada. Other outlets for the study findings are local and provincial organizations such as employment and career development agencies in ....

Depending on the findings and recommendations of the study, another potential outcome is the development of an network that will mentor and advocate for creating a more accessible employment environment for women with disabilities through the use of AT.

2. Scholarly review

This proposed study will serve as the groundwork for the PI's, master's thesis in Women's Studies. *** academic and community co-investigators named are the co-investigators in this proposed study. The proposed study was peer reviewed and will receive external funding from the **funding agency Small Research Grants Awards process pending ethics approval. The literature search consisted of the following three topics:

1. Gender and Employment
2. Women with Disabilities
3. Adaptive Technology

3. Inclusiveness

This research team will recruit women with disabilities from the ** area. The team will select a diverse group of ten women who indicate their interest in participating in the study by responding to the recruitment call. The purposive method of selection intends to bring together women of varying ages and disabilities, employment, educational and training experiences, and knowledge and experience with AT. There will be no discrimination based on disability, ethnicity, race, or sexual orientation.

The ODI advocates using a gender lens for examining disability issues. This government agency reports that 14% of women with disabilities were employed full time in 1995 and that 62% of women with disabilities reported not having worked at any point during that year (ODI, 2002). Because of the high rates of unemployment and underemployment among women with disabilities, this study focuses on the concerns of this population.

4. Competence

Participants selected for this study will not include any individuals who would be classified as a member of a vulnerable population as defined by the university guidelines for ethics review. Special accommodation will be provided to women with disabilities.

5. Age of Consent

This study will address issues of employment and unemployment among women with disabilities.

All participants will be between the ages of 19 and 65 years of age at the time of the study and will therefore be of the age to give informed consent.

6. Free Consent

Individuals interested in participating in the study will complete the Application to Participate form (Appendix B). Applicants may choose not to answer any given question on the Application to Participate form. This may or may not be a factor in the selection process. The research team will review the applications and identify a list of potential applicants.

The PI will review consent form with the prospective participant during an initial one-on-one telephone contact or via preferred method of communication indicated by the applicant on their application form. The PI will answer honestly and freely questions asked by participants. The PI will ask the individual if she consents to participate in the study after the individual has reviewed information about the study as outlined in the letter of invitation and engaged in a one-to-one discussion with the PI.

If, when speaking with an applicant, the PI believes that the applicant feels the applicant is being coerced or pressured to participate, the PI will thank the applicant for their interest in the study and remove their name from the list of potential participants.

Upon arriving for the first focus group meeting, the PI will give participants another opportunity to ask questions about the study before signing a written consent form (Appendix D). Individuals who are unable to sign a consent form will give consent in the form of their choosing.

At the beginning of the AT workshop and the two focus group meetings that follow, the PI will review the rules of engagement as discussed by participants and confirm their continuing interest in participating. Participants will not be required to answer any questions or enter into discussion if they do not wish to do so.

The following decisions about payment (and non-payment) of disability accommodation are based on the policy established at the Centre. Each participant will be reimbursed up to $5.00 for transportation costs for each focus group meeting or workshop session they attend. This is the amount charged by the disability transportation system for a return ticket. Participants using a bus or private transportation will be reimbursed for their transportation expenses up to a maximum of $5 for a return fare for each focus group meeting or workshop session they attend. A participant who incurs childcare expenses will be reimbursed $6.00/hr for each focus group and workshop session they attend up to a maximum 8 hours. Reimbursement of transportation and childcare expenses will be made in cash at the beginning of each focus group or workshop session in which those costs are incurred. Women who require attendant care services will be responsible for their own arrangement and payment of care, as per usual. Further discussion and clarification of reimbursement of cost will take place during the first focus group meeting.

All study participants will be treated fairly and equitably. To ensure positive and equitable access to communication for all participants, communication accommodation such as sign language interpreters or alternate formatting (Braille) will be provided at no additional cost to the participant.

An honorarium of $50.00 will be given to each participant who is accepted as a participant in this study. The PI will inform the participant about the honorarium after the individual agrees to participate in the study. All participants who agree to participate in the study will be paid the honorarium whether or not they complete the study. In other words, a participant may leave the study at any time and for any reason, and will still receive the honorarium. Data collected from participants who choose not to complete the study will not be included in the study findings.

7. Informed Consent

The Centre will distribute information about this study (see Appendix A) to its members and to other disability organizations through the C entre networking (faxes, emailing, web site links, public announcements, bulletin boards etc). Individuals who are interested in participating will complete an Application to Participate form (Appendix B) and return it to the Centre. Information will be distributed for a three-week period. If, after this period of time, there are fewer than 10 expressions of interest, information about the study will be advertised in the public service announcements section of the local papers.

The research team will select the list of potential participants. The PI will contact each prospective participant by telephone or preferred method of communication as indicated on the Application to Participate form. Each participant will be asked if she is able and willing to participate in the study, which is expected to begin soon after ethics approval and finish within the next 12 months. The primary researcher will review with each candidate her completed Application to Participate Form (Appendix B). Once it is confirmed the woman has agreed to participate she will be informed again about transportation and childcare reimbursement. At the time of acceptance into the study, each participant will be informed she will receive an honorarium of $50.00.

Women who apply to participate but are not selected will be notified by phone or via desired format (example TTY, a phone system for deaf). These women will be asked if they wish to receive a copy of the final report. All women that indicate they wish to receive a copy of the report will be given one in the format of their choice.

The PI will review the information about the study and respond to any questions posed by the prospective participant. Each participant will be asked individually to indicate they understand what expenses are reimbursed and what are not. The PI will ask if the individual is still interested in participating. If she is, the participant will be invited to meet with the other participants at the Centre at the designated date and time (TBA).

8. The Process of Obtaining Consent

Each selected participant will be given a copy of the Consent to Participate form (Appendix C) in the format of choice. During a telephone conversation or in person, the PI will review the consent form with each individual participant. The participant will be asked if she has any questions. The PI shall answer these honestly and freely. The participant's understanding of the form will be verified verbally (or in preferred manner of communication). The prospective participant will be asked if she still wishes to participate. If she agrees, she will be informed of the date and time of the focus group meetings and the AT workshop. She will be informed of maximum transportation and childcare reimbursement.

During the first focus group session, the consent to participate forms will be reviewed. The PI will review what it means to provide free consent. The PI will ask if there are any questions or concerns. All questions will be answered honestly and freely. Participants understanding of the form will be verified verbally or in preferred manner of communication. Participants will sign the consent forms after they are satisfied that all their questions are addressed. Individuals who are unable sign written forms will give consent in the format of their choice. Copies of a signed consent form will be given to the participants either at the end of that session, through the mail, or distributed during the second meeting.

9. Documentation of Informed Consent

Each participant will be given a signed photocopy of the consent form. The original will be kept by the PI and store in a locked desk with other study documents. Consents recorded in alternate formats will be copied in the same format, interpreted for researchers in the event it is a Braille copy, and all materials will be stored in a locked desk with other study materials.

10. Outcome of the Consent Process

Each participant will be informed she may withdraw from the study at any time, without prejudice. If a participant withdraws from the study, her data will not be included in the study. Participants will be provided this information in the first focus group and subsequent sessions. Contact numbers for the PI and Co-Is will appear on all communication with the participants. Participants will be encouraged to contact the PI or her academic supervisor should they have any questions or concerns about the study or their participation at any time during the process.

Only the PI, her academic supervisor, and the typist will have access to original data. Transcripts of original data collected in audiotapes and hand-written notes will be shared with study participants, researchers, alternate formatters, and typist. At that time, participants will make any desired changes to the text that more closely reflect their beliefs and attitudes at the time. This is one way of ensuring valid findings. No one will be able to alter data of another participant. Starting with the second meeting, transcripts from the previous meeting will be available for participants to examine. During the final meeting, participants will be formally asked to review transcripts.

11. Harms and Benefits

This study may afford participants three direct benefits. This study will:

1. grant participants occasions to share their knowledge about disability, employment, unemployment, and AT.
2. offer a venue that supports the transfer of AT skills.
3. provide an opportunity to document lived experiences of participants. These experiences will specifically discuss employment/unemployment and underemployment and use of AT.

Development of a disability and chronic illness has severely limited the PI's ability to secure employment in any area of interest. Other individual's with disabilities will also report difficulty gaining permanent, and full-time employment. However, the opportunity to discuss personal, lived experiences about employment, unemployment has not been widely available within the (local) disability community. The participants will be granted a venue to express their voice, opinions, experiences, and thoughts within (at least) a group format.

A second benefit of this project will be that an AT workshop will provide study participants an opportunity to learn about AT and interact with other individuals who may use different forms of AT. It is continuously stressed the word 'expert', defined with a disability lens, is always the person who uses the technology. However, within the ** computer site there are individuals who have gathered a vast expertise in the AT area simply by exposure to so many unique combinations of the technology. Participants will be able to meet with and discuss areas of interest with these individuals.

The third benefit is that lived experiences will be documented. Participants will have control throughout the data collection and analysis process. Participants will be provided a draft for their approval and editing. Participants will receive a copy of the final draft. With their approval, information participants wish others to know about their lived experiences with employment, unemployment, disability, and AT will be widely disseminated.

There are indirect benefits to the wide dissemination of study findings. Study results will be disseminated to disability organizations, perspective employers, employers, and policy makers who will hear information regarding the lived experiences those participants choose to share. Participants will be exposed to the academic expertise and experience of participating in a research study. In return, researchers will gain insight into the perspectives of the participants, their lived experiences, and exposure to disability literature/research and disability language. Some participants may not familiar with the Centre and services it provides. Such exposure will inform individuals not directly associated with the centre, information about its philosophy and services.

It is not anticipated that this research project will cause participants any harm to their physical, psychological, or mental health. A participant may withdraw from the study at any time, for any reason. Participants will not be coerced in any manner.
Transportation will be via a public transit system or privately arranged travel. Reimbursement of transportation and childcare expenses will be made to each participant to a predetermined amount. This information will be freely given to each prospective participant before consent to participate form is completed. All focus group meetings and workshop will take place within a public space. All participants will be treated with respect and dignity.

All participants will be informed, during the first and subsequent meetings that they may withdraw from the discussion area at any time. Participants will also be informed that they may voice issues privately with the PI immediately after focus group meetings or at a mutually agreed upon time.

Participants will be told about the Centre Peer Support Program. This is a service that connects individuals who wish to talk about specific issues with peers who may have had similar experiences/feelings. All study participants may access this service free of charge.
Due to a liaison with **the university, the PI will be in position to participate in this study as a researcher. But, due to disability, the PI has lost employment within her professional field of employment and has been unable to regain employment in a field of her choice. Thus, the PI is personally able to relate to the topic of this research through the lens of a participant. "In feminist participatory research, the distinction between the researcher(s) and those on whom the research is done disappears, to achieve an equalitarian relation, the researcher abandons control and adopts an approach of openness, reciprocity, mutual disclosure, and shared risk" (Reinharz, 1992, p. 181).
Historically, the disability community has viewed research on disability issues via academic researchers as having the potential risk of misrepresentation. DAWN Canada discusses

problems that have been experienced by women with disabilities in the past concerning research. "Women with disabilities have had almost no opportunity to provide correct information or to challenge non-disabled and/or male interpretations of our experiences. Consequently, much of the existing body of research, which normally provides a reference point for new research, must be open to reassessment" (Meister, 1999 downloaded from www.dawn.thot.net/Ethical.html, July 5, 2004). In his book, *Nothing About Us Without Us*, James Charlton (1998) also discusses the issue of self determination in the sense that people with disabilities need to be and should be the leaders in theorizing and describing the conditions of life for women and men with disabilities. With this type of attitude prevalent within the disability community, researchers, and community partner, the Centre believe direct involvement and familiarity with many people with disabilities are research assets.

Recognizing and operating within the IL lens will minimize risk. This will be accomplished in part through inside knowledge of the disability community and personal belief and commitment of the researchers, to the value of IL principles. This is further reinforced by inclusion of a community partner (Centre). The principles of IL are so important to a study that they are reflected within the study title.

The Centre and PI will write a brief (informal) working agreement upon ethical approval concerning boundaries of this study. One part of this agreement will address a conflict resolution process. In the event of a conflict arising, both parties shall find a mutually agreed upon, and independent party to mediate a resolution.

12. Limits to Confidentiality

A small disability community makes it more likely that study participants will know each other and be identifiable within and beyond the community. Participants will enter the study with this knowledge. Often members of the disability community accept that their disabilities makes them 'unique' within a greater society and therefore participants might choose to 'put a face' on their work. Participants will be informed of options available to protect participant privacy and confidentiality as much as possible. Options will include identification by name and disability, by disability only, by pseudonym, or by some other agreed upon process. During the first focus group and subsequent meetings, participants will be offered choices as listed above, we will discuss the choices and than decide collectively the manner we wish to proceed.

Three focus group meetings and one AT workshop are planned. Ground rules about privacy and confidentiality will be established and confirmed by all participants during the first meeting and throughout the project. Confidentiality will be frankly discussed in focus groups and participants will be informed special care will be taken to remove identifiers in any published report. Participant control in formulating a published report, will aid in increasing confidentiality of participants in the summary report.

Research participants will be asked to keep confidential all personal information shared by the researchers or other participants during the focus group meeting. The need to ensure privacy and confidentiality will be discussed during telephone contact and during each focus group meeting or any other type of mutually agreed upon exercise. Problems with violation of confidentiality will be discussed within the group. If privacy is violated, discussion and determination of action will occur at group level.

A typist hired for this project or the PI will transcribe the tapes and handwritten notes taken by note taker. Study participants, researchers, the typist, and individuals who place the materials in alternate format are the only people who will have access to these original data. Alternate formats will be provided by the ***Centre. During transport, notes and tapes will be locked in researcher's briefcase during transport. The audiotapes, notes, and transcripts will be kept in locked storage when not in use and will be destroyed seven years after completion of the project. Electronic records (3) will be saved on the researcher's computer hard drive (1) and back up floppy disc and as information grows on a CD. Computer access is password protected. Computer floppy discs will be kept in a locked cabinet in the researcher's home study. All materials used or gathered throughout this research study such as audiotapes, written notes and transcripts (but not limited to) will be destroyed or shredded seven years after completion of the research study.

13. Barriers to Anonymity

Given the rarity and distinctiveness of some disabilities, the close-knit relationships among members of the disability community, the relatively small catchment area from which the study participants will be recruited, and the face-to-face nature of the focus groups, there is a good probability that two or more participants may know each other. All these factors are barriers to anonymity. A discussion of these barriers will occur during the initial contact with potential participants, during the first focus group meeting and later, as warranted.

14. Conflict of Interests

This research study is a collaborative effort that intends to build partnerships between the academic and disability communities and lay the groundwork for partnerships with government and potential employers. The PI is a graduate student enrolled in the Women's Studies Programme at ** unviersity. She is also a member of the Centre , serves on numerous committees and holds a seat on the ** Centre Board of Directors. This community involvement will be an asset to building partnerships and gaining access to do the research.

To avoid any perceived conflict of interest the PI has resigned from the Board in anticipation of ethics approval to proceed with the study. The PI will be available to provide updates and answer general questions about the study on a quarterly basis or upon request of the Centre Board. Updates or any such presentation will be general and will not address specific and/or confidential materials covered by participants within focus group sessions, or other methods of data collection.

Due to the broad scope of people who support the Centre, it is anticipated a number of participants may have been in the past, or are board and/or Centre committee or staff members. Participants may also be on the Board of Directors of other equality seeking and/or disability organizations as well. Participants are chosen from characteristics previously identified rather than organization affiliation. Participants of this study will not be identified within focus groups or otherwise by positions they may or may not hold in disability organizations.

15. Additional ethics review

Documentation of approval by ** university Ethics Committee is sufficient ethics approval to obtain the small grants award from the external funding body ***funding agency.

Documentation of approval by University Ethics Committee is sufficient ethics approval for research partner, Centre.

16. Contracts/Agreements

This study, its goals, and methodology have been tabled into the Centre Board of Directors minutes during the spring meeting, 2003. At this time, the Board endorsed the study. Starting in September, some new members will be on the Centre Board of Directors. The PI will provide the Chair of the Board a summary of description of the study, goals, process, general outcomes and methods of dissemination, as well as progress to date (since last report). No confidential or information specific to participants will be given at this or subsequent Board updates. Upon completion of this research study, a summary report will be presented to the Board.

An agreement will be issued by ** funding agency once ethical approval is granted. (See letter of acceptance.)

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