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‘What am I... for her?’ Feminism and Disability with/in the Postmodern

**A Thesis presented in partial fulfilment
of the requirements for the degree of
Doctor of Philosophy
in Social Policy at
Massey University**

**Michelle Lunn
1997**

Dedication

This thesis is dedicated to the women who participated in this study. Although you remain anonymous you are the co-authors of this study.

Abstract

A feminist postmodern analysis of the lives of women with physical disabilities is presented in this thesis. Postmodern feminism provides a framework through which the lives of the six women who took part in this study can be understood. Political strategies and interventions are conceptualised and interwoven with these understandings of the participants' lives. The discursive practices operating to produce the subject position 'woman with a physical disability' are described and analysed. It is argued that a postmodern feminist analytical framework is appropriate in this analysis as it is sensitive to the ways in which power works to constitute particular subjects, and alive to the multiplicity and diversity of everyday life.

The production of non-disabledness as the norm and disability as the Other to, or opposite of, this norm is called into question in this thesis. The ways in which this research project, as undertaken by a non-disabled researcher, impacts upon the production of disability as Other, or the question of, 'what am I... for her?' is central in this analysis. This thesis examines the question of, 'what am I... for her?', in relation to 'identity', 'the body' and the construction of 'the self'. A participatory research method, designed to mediate relations of power between 'the researcher' and 'the researched' provides a foundation for this study. This participatory method is designed to insure against appropriation of the voices of the research participants.

This thesis aims to contribute towards the realisation of the aims of disability politics and feminism by making links between the two bodies of knowledge that foster political interventions at all levels of the social network.

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This thesis records a segment of my own feminist journey. I wish to acknowledge a debt to the rich history of feminist authorship that inspired and encouraged this journey. Feminist authors read in bed in the early 1980's, such as Mary Daly and Robyn Morgan are as much a part of this project as the postmodern feminists of the 1990's, studied, pen in hand, at my desk. In the course of this journey my feminist perspectives have continued to change and develop. The particular perspectives of the women who took part in this study have become a part of my feminist perspectives. Thank you, my journey now continues with an enhanced vision.

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Introduction

The title of this thesis poses the question of ‘what am I.. for her?’ in terms of the productive possibilities a dialogue between postmodern feminism and women with disabilities might produce. This dialogue takes place with/in the postmodern¹. The writing strategy utilised in the word with/in signifies *both* that I consider that we live in a postmodern era *and* an indebtedness to modernism. I argue that the *post* in postmodernism does not signify a radical rupture, or break, from modernism or Enlightenment thought. Rather a postmodern analysis calls some aspects of Enlightenment beliefs into question (such as the bases upon which we make truth claims) while retaining others (such as the hope for a more just society).

The Enlightenment tradition in postmodernism is important in this thesis. Feminism's quest for a more just, or egalitarian society, has its basis in Enlightenment thought. In this study, this feminist quest is pursued at the site of ‘the self’, or how we come to understand selves as constituents of community. Another important aspect of this Enlightenment legacy is the question of *what* we are in this very precise moment in history (Foucault, 1982). In this thesis a politics of the self or selves, conceptualised in the question of ‘what am I... for her?’, is presented as a ‘...practical critique that takes the form of a possible transgression’ (Foucault, 1984:45) of the limits of ourselves and the possibility of going beyond them.

This study is located at an intersection between the lives and politics of six women with physical disabilities and my particular postmodern feminist perspective. A feminist postmodern analysis of the issues raised by the women who took part in this study is offered. This study is premised on my own recognition that neither feminism nor disability politics have traditionally catered well to the particular needs of women with disabilities. A gap in theoretical and political knowledge as it relates to women with disabilities can be identified. Disability politics and feminism have not catered well to the specificities of the lives of women with disabilities. It can be argued that in

¹ Postmodern and poststructural analyses have been utilised in this study. Postmodernism and poststructuralism are not the same thing. Postmodernism or ‘the postmodern condition’ (Lyotard, 1984) can be understood as covering a wide range of disciplines including, science, literature and the arts. Poststructural analyses on the other hand can be located within particular theoretical traditions within the social sciences. For the purposes of this study, postmodernism can be read as inclusive of poststructuralist analyses.

disability politics, disability is privileged, while in feminist politics, woman is the primary category of analysis.

A theoretical framework which allowed me to work with these theoretical and political elisions and also to move beyond them was required. A feminist postmodern perspective allows an analysis that does not try to reduce experiences of oppression to pre-given fixed categories such as class, sex, and ethnicity. A particular postmodern feminist analysis has developed from the practices of applying postmodern feminist perspectives to the lives and analyses of women with disabilities. Feminist postmodernism was chosen on the basis of its ability to cater to the multiplicity and diversity of the lives of women with disabilities.

This thesis problematises the ways in which my perspective on the issues, as a non-disabled feminist, differs from the perspective of the women who are a part of this study. Concerns raised in disability politics about the place non-disabled people should occupy with regards to disability politics, and within feminism, in terms of appropriation of the voice of the Other, underpin this perspective.

It is my contention that a dialogue between feminism and women with disabilities has productive possibilities for both women with disabilities and feminism. My interest in this area was sparked by a combination of personal and theoretical factors. Feminist theory has always held a fascination for me. Radical, liberal, and socialist feminist texts and publications provided the background to my interest in feminist studies. The particular academic feminist environment I found myself in at Massey University offered a variety of familiar theoretical perspectives, and also introduced me to a postmodern perspective that I had previously only encountered in the context of visual art. My understanding of postmodern theory developed significantly through an exploratory exercise that required a feminist interpretation of the issues surrounding the barriers to employment, experienced by women with disabilities. Feminist postmodern theory made sense of the issues and allowed me to theorise these experiences from a much wider perspective than the gender, class, and ethnicity categories offered by other feminist theorists. The impact of education policies, living circumstances, ableist expectations, and the attitudes of health professionals could all be theorised in terms of discourses that affected the lives of women with disabilities in material ways.

From a more personal perspective learning about the lives of women with disabilities helped me to understand my own experience of illness and recovery. I could identify with accounts of the marginalisation women experienced as a direct result of non-disabled people's perceptions of their bodies and bodily abilities. My own struggles, through the months of recovery, to be comfortable with my weak, emaciated body, pallor and lack of hair; the difficulties I experienced in relation to needing to ask for assistance, and other people's perceptions of my identity and social role, are all issues women with disabilities speak of. My experience of being perceived to be a person with a disability highlighted for me the differences between the way non-disabled people and people with disabilities might see the world and the importance of recognising these differences in theoretical interpretations. This study is premised upon the understanding that feminist postmodernism holds the potential to offer frameworks and interpretations that can be utilised to productively theorise the lives of women with disabilities.

Postmodern Feminist Perspectives

This study is influenced by the work of a variety of theorists. Disability theorists, feminists and mainstream Foucauldian theorists and commentators (including Michel Foucault himself) are called upon. In many instances I have deliberately used feminist interpretations of Foucault's work rather than drawing directly from his texts. This reflects my concerns about the failure of Foucault to take women into account. Despite the fact that Foucault's writings have been put to work for feminism, he was a profoundly androcentric writer (see for example, Morris, 1988, McNay, 1992). As Morris (1988:55) states, '...any feminist drawn to sending love letters to Foucault would be in no danger of reciprocation'. Feminist theorists have begun using his work for feminist ends, and rather than reinventing these texts my concern is to apply these existing analyses to the research at hand.

A flexible theoretical framework capable of speaking to the lives of women with disabilities in positive ways and of analysing and catalysing political activity on a variety of levels was required. The postmodern feminist framework utilised in this study attends to the differences between and within women. Life for a woman with a disability may develop along trajectories peculiar to the experience of being a woman and having a disability. Issues, that do not feature in the lives of non-disabled women or men who have disabilities, may arise.

Rather than analysing common disparities between the lives of women with disabilities and others, this analysis considers the ways in which these different subjectivities and experiences are discursively produced.

I do not claim that feminist postmodern theory holds all the answers, but as part of a theoretical framework, it can be used to advantage to talk about the lives of women with disabilities. The theoretical perspective offered in this study continued to change and evolve over the course of the study in response to the requirements of the emerging research.

Exclusionary Practices

The Significance of the Signifier 'Participant'

The ways in which the research subjects participate in the research is also a site at which practices of exclusion can occur. Traditionally people who are studied in a research project are termed the research subjects. Feminists (from Oakley, 1981, to Reinharz, 1992) argue against this on the grounds that in the past researchers have tended to treat women as the objects, rather than subjects of the research. The term 'participant', as it is used in this study, is intended to acknowledge the active participation of the people who are the *subjects* in the research.

The use of the term research 'participant' is not unproblematic. The participants in this project include the six women with physical disabilities who took part in the research project, my supervisors, Robyn Munford and Julie Boddy, and myself, the researcher. However, for the sake of clarity, the term participant is used to signify the six women who were interviewed in this study and shared their time, knowledge, hopes, theories, dreams, critiques, and analyses with me. The participants in this study did not merely respond to pre-set questions, rather they took an active part in directing the focus and content of the research. The underlying principle of inclusion informing the choice of the term 'participant', permeates all aspects of this study, from the choice of research strategy to the manner in which the interviews were conducted. I argue that problematising research principles and terms of reference is one means by which practices of exclusion might be challenged. Other practices, including choices and uses of theory, also serve to maintain the status quo. The ways in which choice of

theoretical frameworks influence the outcomes of the research is discussed in Chapter Three.

Postmodernism, Feminism, and Exclusion

Another concern in this thesis is that the feminist postmodern analytical framework is presented in such a way that it does not alienate people who do not have a specialised knowledge of postmodern theory. The profusion of obscure words and phrases, and words which have precise meanings (that are not specifically defined in the body of the text) often act as a deterrent to engagement with postmodern theory. I have attempted to mediate the exclusionary nature of the language in which much postmodern theory is presented. A point worth noting with regard to this thesis is that Foucault himself is often easier to read than the theorists and commentators who write about his work.

The feminist postmodern perspective utilised in this study was presented to the research participants in the follow-up interviews. The problems I experienced, trying to translate complex theoretical ideas into accessible language and concepts, suggested a need to pay attention to writing strategies. If this study was to achieve its political objectives, then an attempt to mediate the line between the necessity for a precise theoretical language and accessibility needed to be made.

Problematizing Pakeha Elisions²

It has been suggested that exclusionary practices occur in relation to the use of inaccessible language or theories. The choice of who to research and how this research is carried out is also a potential practice of exclusion. There is a tendency within feminist writing to speak of various experiences of marginalisation as if they have an additive value. Thus, ethnicity, class, relative economic wealth, age, and disability are added into existing analyses with little apparent understanding of the specific issues at hand. While there may be similarities in many experiences of oppression, homogenising the issues in this way can work to obscure the sources of such problems.

²The title of this section refers to practices that mask the voices and realities of non-Pakeha. Practices such as taking Pakeha experience as the starting point for research and analyses, are a part of the processes which serve to elide the voices of Others.

I wish to acknowledge that a bi-cultural analysis is significantly absent from this thesis. The concerns raised above explain, but do not excuse, the lack of cultural analysis. This lack reflects my own lack of personal knowledge and skills and the fact that the participants were found through my own social networks. My position within a predominantly Pakeha, middle class academic institution influenced the choice of participants. I attempted to find women from other than Pakeha backgrounds and succeeded in that one of the participants is Maori. However, as this participant was raised in an institution removed from iwi and whanau, she tended not to raise issues that required cultural analysis.

It can be argued that the lack of analysis of the issues of particular relevance to Maori women with disabilities contributes towards racist practice, in that Pakeha issues and values continue to predominate. I talked of these issues with Maori oral historians in Palmerston North. From our discussion it became clear that an understanding of cultural context is a prerequisite for the gathering of quality information (Pewhairangi & Pewhairangi, 1996³). Affiliations, or connections to the participants' iwi emerged as important aspects of the research process. Raising awareness of the needs of Maori women with disabilities, and women from other ethnicities who have disabilities, are issues that need to be addressed. Building upon the concerns raised in this study, research in this area would need to begin from the experiences of Maori women with disabilities.

Exclusions and Inclusions

What is left out of this study is as important as the material that is included. The discussion above of exclusions, elisions and literary signifiers, serves as an introduction to the politics of what is left out. The politics of what is included; feminism, postmodernism, non-disabled perspectives and six women with physical disabilities, is touched upon briefly in the opening pages of the introduction. The choice and use of the method also influences the processes of exclusion and inclusion. Choosing what to include impacts upon and is in turn impacted upon by the method. As well as determining the final form of the research, styles and methods of researching can be seen to be part of the processes of inclusion and exclusion. The participants influenced the research design and participated in the analytical components of the study.

³Pewhairangi, Irene, & Tu Pewhairangi (25 May 1996 10am-12 noon). Meeting about Maori Oral History Research.

My reflections on the method also contribute to the final form of this thesis. The particular participatory method utilised in this study reflects a process of identification of the problems inherent in existing research practices - for women and for women with disabilities - and a simultaneous search for research methods which work to move beyond these problems. Appropriation of the voices of Others emerged as a major problem in this study. This includes speaking for Others, or on the behalf of Others, but not speaking from their perspective, or about issues that are important to them. This thesis foregrounds issues identified as important for women with disabilities. These issues were identified by the research participants and in the literature by and about women with disabilities.

This study was designed for the purposes of speaking about women with disabilities within a postmodern feminist framework, while simultaneously seeking to avoid sliding into practices of appropriation. As a consequence, searching in the gaps between the myths of disability and the everyday lives of the participants was a fundamental concern in the development of the method. This study problematises practices that situate non-disabledness as the norm, and disability as the Other. The principle of avoiding appropriation of the Other guides every aspect of this study, foregrounding the question of, 'what am I... for her?'

The Structure of the Thesis

Presentation and Layout

This thesis is divided into four sections. Chapters One and Two in Section One present a discussion of the theoretical perspectives informing the research. Section Two presents the theoretical constructs informing the research and the application of these constructs through the method. Section Three presents an analysis of the information gathered throughout the research project. A postmodern feminist interpretation of this information, drawn from the theoretical information discussed in Chapters One, Two and Three, is presented alongside the stories and analyses of the participants. The final section begins with a reflection on the method in Chapter Eight. Chapter Nine offers some final thoughts on the study as a whole and outlines possibilities for the future.

Theoretical and Methodological Constructs

The theoretical perspectives I have chosen to use in this study are revealed in the first three chapters of this thesis. These first three chapters document my path through the theoretical terrain chosen for this study. The information presented in Section One relates to the major theoretical concerns structuring this study. The theoretical information presented in the first chapter discusses issues concerned with identity, disability, and the body.

Identity is an important construct in both feminist and disability circles, where the possible uses identity can be put to in the service of emancipatory politics and the problems associated with a politics of identity, are the subject of vigorous debate. Looking specifically at identity issues as they are presented in feminist theory provides the framework for a theoretical examination of the way identity currently functions in disability theory and politics.

Feminist analyses of ‘the body’ and the ways in which discourses speak through the body can be used productively to analyse the experiences of women with disabilities. The body is analysed in terms of a Foucauldian understanding of the way power⁴ works through the body. This theoretical analysis of the body is important as a deconstruction of what it means to have a physical disability in Aotearoa/New Zealand, and raises a wide variety of issues concerned with the constructedness of the body and relations of power and powerlessness.

The following chapter, Chapter Two, considers selves and communities within the context of the self theorised as a constituent of communities. The theories of the self offered in this chapter both complement and move on from the identity/difference debates. This chapter extends the analysis of power begun in the preceding chapter and develops the notion of resistance within relations of power. The self is considered as a site at which politically salient outcomes might be generated.

⁴ Rather than being coercive or dominating, power in this thesis, is defined as something that occurs in all human relationships. This use of the word power, is derived from the work of Foucault. In his analyses Foucault suggests that *power* should be understood not as a thing in itself but as a *relation*.. Foucault’s analyses are concerned with relationships of power between human beings, occurring throughout every social field (Foucault, 1988b).

An analysis of relations of power continues to inform the following chapter. This chapter, Chapter Three, documents my engagement with a section of methodological material relating directly and indirectly to participatory research practices. Identity, the construction of selves, and relations of power, are theorised in the opening chapters of this thesis. These constructs are particularly relevant to my choice of a research method. Owing to the fact that understanding the meaning of identity is seen as important in this study, a method that took differences in identities into account was needed. It is argued that because having a disability leads to specific experiences of marginalisation, the method needed to incorporate an understanding of relations of power and powerlessness. From this matrix of complimentary and contradictory theoretical, personal, and substantive⁵ positionings, a particular and partial postmodern feminist position emerges. This particular position is reflective of my postmodern sensibilities, feminist beliefs, and an engagement with a variety of material relating to the experiences of women with disabilities. In Chapter Three this particular and partial framework is utilised, discussed and further explained. The methodology continues to set the scene for the collection and analyses of information in the following chapters.

Using a Participatory Research Method to Understand the Lives of Six Women with Physical Disabilities

The method emerged as an important aspect of this study. The story of the method is told in Chapter Four. The particular method used in this study needed to be responsive to issues of power in both the research process and the researcher participant relationship. The question of authorship, raised in Chapter Two, is particularly important in the application of the method. The division between myself, as the author/authority of this thesis, and the contribution made by the research participants, is called into question. A postmodern feminist analysis of this problematises the modernist notion of the neutral and unbiased researcher, suggesting that relations of power are involved in this objectivisation of women⁶. In response to critiques such as this, a method that allowed me to simultaneously write relations of power into the research process and try to mediate these relations of power, was required.

⁵The term substantive is used in this study to signify a commitment to grounding the research in the everyday realities of the research participants.

⁶See Chapter Two for a discussion of this.

A concern to ensure that the research process did not present the research participants as the objects of the study motivated the choice of a multi-layered method. The research method, and the depth of commitment the project entailed was explained to the participants at the onset of the Life History interviews. The method involved repeat interviews, in which the theoretical material and methodological processes of the study were shared with the participants. Participants had the chance to comment upon, and critique my interpretations of the information they shared, their own and other participants stories, comments and analyses. In order to ensure that the issues raised in the research were important to the research participants, the research began with a Life History project, in which the participants were encouraged to speak about their lives and to raise issues they considered to be important in terms of being a woman and having a disability. This was followed by an individual interview in which we discussed the issues I had identified as important, or major from the Life Histories, in terms of their relevance or importance to each participant.

A participatory research method set within a feminist postmodern framework structures the gathering of information in the substantive components of this study. There is no tried and tested blue print to follow in my choice of research method. The method developed from the moral and ethical concerns raised by, and through, the theory. A methodology such as the one utilised in this study, begins from sensitivity to power relations and the specificities of the issues relevant to the lives of the research participants. Rather than providing a template for further research, the method should be regarded as a starting point from which future participative studies can grow.

Presenting, Theorising and Constructing an Analysis

The information in Chapters Five, Six, and Seven, is presented in a manner that links it to the main theoretical concerns addressed in this thesis. Identity, the body, and the self, are the central constructs around which the analyses are organised. Chapter Five addresses identity issues and theorises these in terms of feminist postmodern understandings of identity. The ways in which identity functions as a political tool is particularly important in this chapter. Chapter Six foregrounds the body in terms of non-disabled peoples' perceptions of people with disabilities. Non-disabled people's assumptions about and responses to people with disabilities, and the ways in which discourses work through and on the body to produce certain understandings of disability, are discussed in this chapter. Chapter Seven deals directly with issues of power. The participants'

discussions of power speak directly to the issues raised in Chapter Two's discussion of selves and communities. The participants' analyses of the ways in which disability is defined in relation to non-disabledness, and the means by which such divisions are maintained and resisted, are the subject of this chapter.

Conclusions and Afterwords

Section Four, the final section in this thesis, begins, in Chapter Eight, with a critical self reflexive appraisal of the method. The ways in which methods, research practices and writing conventions produce particular research outcomes is called into question with a view towards future research practices. In Chapter Nine, the final chapter, I look back on the research process in terms of the potential of this study to contribute positively towards the future in terms of political initiatives, and the relationship between the research and social policy development and implementation for people with disabilities. With the hindsight of this study, I explore what the future may hold in terms of dialogues between feminism and disability.

Section One:

Thinking Things Through From An/Other Perspective: Changing the Critical Perspectives On Feminism, Disability and Postmodern Theory

Introduction To Section One

Identity and difference, and differences of identity, ways of thinking through accounts of embodied differences, the politics of selves and communities of selves are considered in the following section. Chapter One looks at identity and difference as inter-related issues, in the process of working towards making changes for women and for people with disabilities. The identity/difference debates are central in feminism's quest to escape the problems associated with conceptualising 'woman' as a stable, pregiven, predetermined category. This questioning of things that have been considered natural or pregiven, is continued in Chapter Two. Chapter Two's discussion of the self continues the foray into alternative conceptualisations of subjectivity. A discussion of subjectivity, agency, and authorship sets the scene for an analysis of the potential the concept of the self as a constituent of communities has to achieve political ends. Foucault's notion of 'the limits' as a site of potentially radical change is discussed in this chapter.

Chapter One

Identity Politics, Disability and the Body: A Non-Disabled Researcher's Path Through The Theoretical Perspectives

Introduction

As a non-disabled researcher undertaking a major research project with women with disabilities the issue of 'identity' is something I feel it is necessary to address before I begin. Identities have meanings attached. For example, having the identity of a person with a disability has a specific meaning within Aotearoa/New Zealand in the late 1990's.

Identity has a variety of functions. Identity can function to make certain actions and behaviours appear appropriate or inappropriate. Identity can open some doors and close others. The central questions underpinning this chapter include: What place does identity hold in disability politics and feminist politics? How am I positioned and how should I position myself with regards to disability politics and people with disabilities? How are identities constructed?

Identity has been a central construct in the formation of both the politics of disability and of feminism. Feminism argues that masculinity is privileged while disability politics argues that non-disabledness is regarded as the norm. Both movements have been built around the questioning of marginalised identities. In this chapter I look at the ways in which identity has been utilised and theorised in disability politics. This is followed by a discussion of the place of identity within feminist politics. Next the feminist essentialism/anti-essentialism debates provide the framework for a discussion of the ways in which identity can be utilised to achieve politically desirable outcomes. Theories of the body and the ways in which power works through the body are discussed in the final section. My concern in writing this chapter is to explore the ways in which disability politics and feminism might inform one another.

Disability Politics

Oliver (1990) and Morris (1991) write of the distinction between organisations of, and organisations for 'the disabled'. Within disability politics a minority group approach to political strategies can be identified. Within minority group politics demands are made on the basis of the unrecognised needs of a particular minority (see for example, Morris, 1989, Cahill, 1991, Wicks, 1991). These authors argue for a politics in which people with disabilities organise for themselves, pursue their own political goals and advocate on their own behalf

on the basis of their own identity. Within disability politics, the notion that the possession of a disabled identity provides a privileged basis from which to articulate an idea or opinion on disability issues is advanced. For people who feel that disability organisations do not cater adequately to their needs, the questioning of the hegemony¹ that non-disabled professionals enjoy in this area is a necessary step towards challenging experiences and perceptions of inequality. In this thesis it is argued that disability is currently defined in relation to non-disabled norms. Non-disabledness is defined as 'normal' and disability is regarded as a deviance from this norm.

The problematisation of a privileged norm and a marginalised Other also informs feminist politics. Feminists from Simone de Beauvoir (in 1949) to the present, have argued that women have been defined negatively. Man is the privileged signifier and woman is the negated 'Other'². Feminism challenges the idea that 'man' should be defined as the subject or the norm while 'woman' is labelled different and therefore deviant. Schur (1984) writes that for women, being labelled as deviant has been a standard feature of everyday life. Deviance-defining is also seen to occur with respect to stigmatised personal conditions such as having a disability (Schur, 1984). It can be argued that the label 'woman' and the 'disability' label are both defined negatively. Feminism too has assigned women with disabilities to the category of the Other. Women with disabilities challenge that feminism ignores their needs and is fundamentally flawed by ableist biases. If feminism always begins from non-disabledness and does not take into account the realities of having a disability then feminism and disability politics may continue to pass one another by. Matthews and Thompson (1993) suggest that while the exclusion of women with disabilities from feminism is not a conscious decision, this exclusion means that the opportunity for exploring our commonalities and differences is lost and as a consequence, women continue to be segregated from one another. The distinction between women with disabilities and non-disabled women can also be seen in feminist research practices.

Morris (1991, 1991-92) argues that the disabled/non-disabled dichotomy is a fundamental assumption in feminist disability research. Often feminism does not

¹ Hegemony refers to the processes by which particular groups in society come to establish their world view as the most appropriate.

² This conceptualisation of woman as 'Other' is often discussed in postmodern feminist discourse.

include women with disabilities in the 'us' category but relegates them to the category of 'the cared for'; 'them' (Morris, 1991, 1991-92). According to Morris, this separation of women, from people with disabilities and older people is evident in most feminist research on caring. This positioning of women with disabilities as 'Other' pervades feminist analyses. The critique of the positioning of women with disabilities as Other in feminist research informs the methodological and analytical components of this thesis.

Hannaford's (1985) prediction that it would take ten years for feminism to consider the significance of disability and to recognise the position of disabled people has proved conservative. It can be argued that disability is only now becoming an issue in feminism. Women with disabilities are similarly disillusioned with the disability movement. They claim that disability organisations do not embrace issues for women with disabilities, nor offer an analytical framework conducive to their needs (Hannaford, 1985, Lloyd, 1992). Men and men's issues dominate disability organisations. Additionally, the models at the forefront of disability thinking have largely been constructed by men (Lloyd, 1992). Morris (1991:9) offers a similar critique suggesting that, 'like other political movements, the disability movement, both in Britain and throughout the world, has tended to be dominated by men as both theoreticians and holders of important organisational posts'. Even the development of new technology is directed towards the needs of men (Oliver, 1990). For example, when technology such as surgical implants involving electro-stimulation of bladder muscles is developed, considerably more are given to men, who need them less, than women who need them more (Oliver, 1990). In reply to this lack, women with disabilities have formed identity based groups such as S.A.D. (Sisters Against Disablement, UK) where the issues of women with disabilities are foremost on the agenda (Hannaford, 1985). Women's issues are also beginning to be recognised in disability organisations, included in conference agendas, and acknowledged by mainstream disability authors.

Women with disabilities are beginning to articulate their needs and to question both ableist and sexist norms (Campling, 1981, Hannaford, 1985, Morris, 1991, Keith, 1994, A Group of Women with Disabilities, 1996). This process has the potential to radically challenge feminist orthodoxies. Morris (1991) suggests that integrating disability issues and feminist thought is akin to feminism's political and theoretical challenge to the way that the experience of 'the white male' was taken as representative of general human experience.

Micheline's contribution to Campling's (1981) anthology of writings by women with disabilities illustrates the ways in which this radical challenge might be articulated³. Micheline writes of discovering her feelings of dissatisfaction about her body were not so different from the feelings other women expressed about their bodies. The regulation of women's bodies, epitomised in the struggle for unattainable physical perfection, has the potential to affect the psychological well-being of all women. From a feminist perspective, Wolf (1990) suggests that the current emphasis on physical beauty is a ploy to keep women less free than they otherwise might be, and to divide women from each other as they compete in the beauty stakes. As Micheline and Wolf demonstrate, the myth of the perfect body may be further away from reality for some women than for others. Nevertheless, for all but a very small minority it is unattainable. This discussion of the myth of the perfect body is an illustration of the potential feminism, disability politics, and theory have to inform one another.

I argue that women with disabilities need some basis from which to challenge the hegemony of non-disabledness and phallocentrism⁴. I also believe that non-disabled people can be a strategic part of this struggle at this particular moment in time. Munford (1995:54) suggests that the struggle for women with disabilities:

... is about moving from the position of the 'other' wherein one is assessed against a norm which functions to exclude women with disabilities, and denies women with disabilities the right to be 'natural' participants in our communities, to a position of full inclusion and participation.

In this thesis I suggest that the essentialism/anti-essentialism⁵ debates currently in vogue within feminist circles provide a starting point from which to discuss these issues. An analysis of the concept of essentialism is useful as it informs

³ Ten years later a similar challenge has been popularised by American authors such as Faludi (1991) and Wolf (1990) .

⁴ According to Grosz (1990: 60) 'phallocentrism occurs whenever the two sexes are represented by a singular - or "human" (i.e. masculine) - model. The feminine is defined only in relation to the masculine, and never autonomously, on its own terms. It is represented as either *the opposite* or other; or as a complement; or as the *same* as masculinity' (her emphasis).

⁵ The essentialism/anti-essentialism debates are outlined in detail below.

the closely related issue of identity politics. In this chapter I discuss the strategic use of essentialist notions, in terms of identity politics⁶ and political strategies based on shared goals, in the formation of a politics of change.

At the time I wrote this chapter the anti-essentialist standpoint in postmodern feminist theory had achieved a degree of orthodoxy formerly attributed to radical feminist discourse. Radical feminism insists that the oppression of women is the fundamental oppression. The politically correct views arising from such a standpoint begin from this assumption. This view is regarded as essentialist in that it is suggested that the oppression of all women can be fundamentally reduced to biology. An anti-essentialist standpoint on the other hand assumes that experiences of oppression can be attributed to a wide variety of causes and that gender is not always the primary source of this oppression.

In terms of the idea of creating dialogues between feminism and disability, the following question needs to be asked. If feminism does not cater well for the needs of women with disabilities because it fails to adequately account for their experiences, could a disability politics, in which disability was regarded as the essential or primary cause of oppression be of benefit for feminism? If the answer to this question is no, then identity as a stable and pregiven (or known) entity is not a useful concept for the project of building politically salient dialogues. The following section documents my own engagement with the essentialist/anti-essentialist debates and my struggle within postmodern feminist discourse to find theoretical perspectives which take account of the multiplicity and diversity of women's lives without denying the place of identity in feminist and disability politics.

Identity Politics

Identity politics was the organising principle for radical feminist analysis and is an important aspect of the disability pride movement. Identity politics has been critiqued for elevating ontological⁷ categories to epistemological⁸ status, where *who we are* becomes *what we know*. If we know that being a woman or having a

⁶ A politics organised around a notion of common identity, for example gender, disability, or ethnicity, in which identity becomes the privileged basis from which to speak.

⁷ Theories about the nature of being or existence.

⁸ Theories of the grounds of knowledge, or how we come to know the world.

disability is the primary cause of the oppressions we experience in our lives, then being a woman or having a disability makes us an expert in that area. The knowledges of others are simultaneously invalidated. 'You don't know, because you haven't experienced it', becomes a legitimating strategy. Within a politics based on identity, those outside the magic circle of lived experience are silenced and excluded. However, Fuss (1989) suggests that, although these fictions of shared identity as the basis for knowledge-truths may serve to silence some people, they may simultaneously empower otherwise silent people to speak. For example, within a feminist context, women with disabilities may speak out on an issue which they feel directly affects them because of their disability, when otherwise they may not have been inclined to speak.

Identity politics utilises essentialist categories as an organising principle. The idea that it is possible to attribute certain shared characteristics and values to a group on the basis of a single aspect of embodiment is often deployed. Lorde (1984) writes of the way in which power utilises difference at both an individual and a group level to fragment opposition. As a lesbian mother and partner in an interracial couple, Lorde found it problematic being constantly encouraged to identify one aspect of herself and present it as the meaningful whole. Although one of the participants in this study spoke with frustration about having something to say on topics other than disability, I have not found any texts related to the fragmentation of identities with regards to disability in Aotearoa/New Zealand. However, Irwin (1990) writes of the conflicts involved in being Maori, feminist and lesbian. From these texts I believe it is possible to form a picture of the problems that might be encountered in a disability politics that did not move beyond identity politics.

The Essentialism/Anti-Essentialism Debates

The problems inherent in feminist identity politics are well documented in the essentialism/anti-essentialism debates. Various definitions of essentialism are found in psychological, biological and cultural accounts of difference. For the purposes of this thesis 'essentialism' refers to ahistorical fixed and unchanging characteristics assigned to individuals on the basis of their biological, psychological or cultural attributes.

There are problems with any form of essentialism which have been well documented by postmodern feminists. Segal (1987) argues that essentialist strategies strengthen traditional gender ideologies in their reassertion of fundamental biological differences between women and men. However, many postmodern feminists mediate the essentialist/anti-essentialist debates⁹ claiming that anti-essentialist arguments rely on a more sophisticated form of essentialism. As this chapter demonstrates, while I acknowledge that there are problems with any deployment of essentialist categories, I do not believe essentialist arguments to be *ipso facto* wholly negative. As Fuss (1989:xi) suggests 'the question we should be asking is not "is this text essentialist and therefore bad?", [but rather,] ...if this text is essentialist, *what motivates its deployment*?' (emphasis in original).

A question we need to ask in relation to feminism and disability is how can essentialism (particularly as it relates to identity politics) be used productively to achieve politically desirable goals? Within the society in which we live, having the body of a woman as opposed to that of a man has a specific meaning. Politics based on identity and theories which acknowledge our bodily differences can provide us with viable political tools despite their essentialist underpinnings. My arguments rest on the assumption that there is a need to take our embodied differences and lived realities into account. Essentialism, as I will argue in this chapter, can be used strategically. The following quote by Schor (1989) illustrates why the issue of essentialism (or essentialisms) is important in this chapter. Schor writes:

It is precisely around the issues of differences among as well as within women that the impasse between essentialism and anti-essentialism is at last beginning to yield: for just as the pressing issues of race and ethnicity are forcing certain anti-essentialists to suspend their critiques in the name of political realities, they are forcing certain essentialists to question their assertion of a female essence that is

⁹ See for example, Fuss (1989), Grosz (1990), Soper (1990), Kirby (1991), Radstone (1992), and Spivak (1992) for a discussion of the essentialism/anti-essentialism debates. Rather than a discussion of essentialism or non-essentialism, debate has turned to the notion of essentialism itself. Distinguishing between essentialism as a 'thing-in-itself', or an understanding of essence as something to which women have been historically bound (de Lauretis, 1989) and looking to the uses of essentialism (Fuss, 1989) has emerged as a more productive site of enquiry.

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widely perceived and rightly denounced by minority women as exclusionary (1989:43) (emphasis in original).

Anti-essentialists - those who do not believe it is possible to talk of women's homogeneity - are beginning to see the strategic usefulness of essentialist categories; while essentialists, on the other hand, are beginning to realise that claiming a unitary category of women as the starting point for political struggle does not take into account the multiplicity and diversity of, and in, women's lives.

The impasse between essentialist/anti-essentialist standpoints is sometimes referred to as the essentialist/constructionist debate. Constructionists argue that we are a product of the various discourses which surround us. The categories, woman or disability, for example, have no meaning prior to the ways in which they are encoded in a particular historical moment. For constructionists the notion of essence itself is a historical construct. However, Fuss (1989) Kirby (1991) and Radstone (1992) argue that this essentialist/anti-essentialist debate is not productive for feminism. Fuss (1989) suggests that both constructionist and essentialist positions rely upon essentialist notions of the subject. Constructionism is itself a sophisticated form of essentialism (Fuss, 1989)¹⁰. Fuss uses 'the body' to illustrate this idea:

*For the essentialist, the body occupies a pure, presocial, prediscursive space. The body is 'real', accessible, and transparent; it is always there and directly interpretable through the senses. For the constructionist, the body is never simply **there**, rather it is composed of a network of effects continually subject to socio-political determination. The body is 'always already' culturally mapped; it never exists in a pure or uncoded state. Now the strength of the constructionist position is its rigorous insistence of the production of*

¹⁰ Grosz's (1990) division of 'essentialism' into three categories, biologism, naturalism and universalism illustrates this point. Biologism is defined as a form of essentialism in which women's essence is defined in terms of biological capacities. Naturalism often equates biological and natural properties, commonly attributing a fixed nature to women on the basis of theological and ontological grounds. Psychological or religious 'truths' form part of this category. Universalism usually incorporates elements of biologism or naturalism. However, universalism may be understood in purely social terms. Universalism draws upon cross cultural sensibilities.

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social categories like 'the body' and its attention to systems of representation. But this strength is not built on essentialisms' demise, rather it works its power by strategically deferring the encounter with essence, displacing it, in this case, onto the concept of sociality (Fuss, 1989:5-6) (emphasis in original).

Arguments for the strategic use of essentialism are important as they bring theories of the body back into the political domain. Essentialist categories allow arguments against the notion of the level playing field upon which every person has an equal chance of success. For example, it can be argued that if access to the fundamental rights upon which the level playing field is premised, such as education or employment, are denied to particular groups of people, then the field cannot be entered.

Using essentialism strategically allows the argument that having the body of a woman with a disability has a specific, bodily inscribed meaning. Social constructionists, on the other hand tend to play down the importance the body. Oliver (1990) can be situated within this social constructionist camp. He argues that disability is socially 'created' by the society in which people with disabilities live. The picture of a man in a wheelchair confronted by a set of stairs, on the front cover of the book in question, can be regarded as a representation of Oliver's standpoint. The person in the picture, is disabled by their environment. If a ramp replaced the stairs their impairment would no longer be experienced as 'dis-ablement'. The desired destination could be reached.

The desired destination in this case is a polling station. The picture and Oliver's (1990) analysis also suggest that disability is ideologically constructed. Changing the ideological construction of disability will change the material realities of having a disability. Disability is a construction, created by and through the experience of impairment, within the political, social and material environment within which people with disabilities exist. However, Oliver's strategy fails to take into account the material realities of having a disability. If disability is a fiction created on the basis of impairments, then in order to construct a new social movement around the notion of impairment it is necessary to either move from disability to impairment as a category, or to acknowledge that disability is not wholly socially constructed or created¹¹.

¹¹ See Oliver (1996) and Sullivan (1996) for a discussion of the strategic use of the term impairment. In response to critiques of the social model of disability Oliver offers a social

Otherwise our argument disintegrates into ellipticism, we come full circle back to the position where disabled bodies don't matter, are immaterial anyway. If we can only get the environment right then the experience of disability can be ignored because it has no bearing on lived experience. A position such as Oliver's when taken to its logical extreme does nothing to destabilise the hegemony of non-disabledness.

The preceding critique of Oliver's social constructionist standpoint provides the impetus for further analysis of the strategic use of essentialist categories. In analyses that consider the uses and potentials of essentialist categories the body is forwarded as an important site for analysis. It can be argued that bodies, women's bodies, the bodies of women with disabilities, provide us with possible categories on which to ground political designations.

Essentialism, Anti-Essentialism, Irigaray and Politics

Irigaray, a feminist whose work has generated considerable controversy, would argue for the strategic use of the feminine body to achieve political goals. The essentialism/anti-essentialism debate is often played out around the role the body plays in her work. Some see Irigaray's project as useful for feminism, while others critique her work on the basis of its essentialist tendencies (Fuss 1989, Berg, 1991, Whitford, 1991). Irigaray (1977) uses the lips of the vagina to illustrate her analysis of what it might mean to be a woman. As most authors return to these 'lips', the debate comes down to whether the two lips can be seen as a metaphor (Fuss, 1989). Advocates of Irigaray's analysis argue that the lips are offered playfully, ironically and metaphorically.

Spivak (1992) suggests that Irigaray's critics ignore the role of rhetoricity in Irigaray's prose. Those who oppose Irigaray apply a literal translation to her work. From this perspective the lips of the vagina are symbolic of a biologically essentialist analysis. For these feminist critics, Irigaray's work is not productive as it reinforces traditional gender ideologies and naturalises women's devalued

model of impairment. Oliver (1996:22) argues that 'disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society'. In his analysis Oliver argues that, if you define disability as the outcome of disabling social barriers then their removal will remove disability but leave impairment.

position. An analysis such as this offers nothing to women with disabilities as it merely reinforces the conceptualisation of women with disabilities as 'passive, helpless, dependent and powerless'¹² providing no basis from which to challenge these negative stereotypes.

In contrast to the essentialist readings of Irigaray described above, I argue that her project can contribute towards changing the everyday realities of women's lives. Irigaray's project is to reinterpret the realities of women's lives by exposing the ways in which women's bodies are constituted. Writers like Fuss (1989), Munford (1990), Berg (1991), Whitford (1991), and Gatens (1992) have different readings of the essentialism in Irigaray's work to that proposed by anti-essentialists. For writers interested in the play of essentialism and identity, Irigaray's project does not naturalise biological divisions, play down the differences between women, or obscure the need for political action. Rather, by thinking through difference, it allows the discursive space¹³ for a multiplicity of political strategies.

Irigaray does emphasise the divisions between women and men but offers a diversity of strategies that also allow for the divisions between women. Irigaray argues that '... it is essential for women among themselves to invent new modes of organisation, new forms of struggle, challenges' (Irigaray, 1977:166). However, Irigaray seems to propose this strategy as an interim measure. Irigaray would argue that the challenge of women with disabilities to the non-disabled world is a salient political strategy within the context of the struggle to assert female or disabled subjectivity. However, she suggests that if a dialogue between women and men were truly possible then these separatist strategies would no longer be necessary. If Irigaray's analysis were applied to the politics of disability, a similar prognosis could be made: essentialist politics would become redundant.

One of the major attractions of Irigaray's work is her refusal to define the form that these struggles or challenges might take. While Irigaray proposes these new strategies for women, she does not even begin to tell us how we might

¹² The problems associated with regarding women with disabilities in such negative ways are discussed in the State Services Commission publication, 'The Invisible Minority' (1990).

¹³ This refers to the possibility of speaking, thinking or expressing new, different or challenging ideas, such as the idea that a dialogue between feminism and disability might be productive.

conceptualise the essence of woman. Irigaray is working towards securing woman's access to an essence of her own without actually prescribing what that essence might be (Fuss, 1989). Applying Irigaray's analysis to the question of creating dialogues between feminism and disability it is possible to suggest that women with disabilities might provisionally claim (as they are doing) that they should be 'enabled' to speak for themselves. Once women with disabilities gained a secure position within society, Irigaray would argue that this essentialist standpoint would no longer be necessary. Recourse to essentialist identity based strategies would no longer be required. For example, positive discrimination practices would no longer be required, as support for employment would commence with early childhood and be available throughout a person's lifetime.

In the mean time as Irigaray suggests, struggles for equality need to continue. Having the identity of a woman is clearly important in Irigaray's (1977) analysis; it is the meaning of this category that Irigaray plays with. Irigaray does not preclude the possibility that the subject might possess multiple essences which may contradict or compete with one another (Fuss, 1989). Irigaray offers the following response to the question 'are you a woman?'. '... "I" am not "I", I *am* not, I am not *one*. As for *woman*, try and find out....' (Irigaray, 1977:120).

Postmodern Feminist Politics

A similar practice of using essentialist identity categories as a starting point for political action is proposed by the Foucauldian-feminist author Sawicki (1991). Rather than accepting the notion of fixed or static identities, Sawicki's perspective centres on identities as changing and mobile. This, however, does not preclude the notion of unified political action. Rather, a politics of local discontinuous and regional struggle is advocated. Sawicki is drawing upon Foucault's program of local resistance. Foucault understands power as a relation (or relationships of power) (1988b) which are in a state of constant struggle or flux (1978). Heckman (1990:183) suggests that Foucault's strategy of local resistance is grounded in the idea that 'as contextual, historical beings, launching local resistance efforts against specific regimes is more appropriate, and more effective, than trying to formulate universal theories to justify acts of resistance'.

Utilising Sawicki's analysis, it appears possible to propose that strategies that utilise essentialist notions about a shared identity can provide the starting point for coalition politics based on shared goals. Indeed some of the strengths of the postmodern project are its acceptance of diversity (in this case of political strategies) and its questioning of meta-narratives (that viable politics necessarily originates in shared political affinities). While it can be argued that identity is a source of shared strength, the sharing of diverse identities and a politics built around common goals is potentially a source of greater strength.

A Foucauldian analysis of the processes involved in such political strategies would talk of power relations as more than simple relations of power and powerlessness where various agendas materialise into particular, geographically and situationally specific, multiple and contingent, but politically viable outcomes. Such an analysis would talk of multiple points of resistance in which power exists as '...tactical elements or blocks operating in the field of force relations...' (Foucault, 1978:101-102).

One such tactical element or block might be conceptualised as the question of 'what am I... for her?' in a politics that seeks to make connections across the borders of identity categories. Looking beyond identity politics to the idea of making links across identity boundaries by exposing the common interests of a diverse group of people provides a basis for collectivist politics. Such a politics might work by focusing upon the common interests. In terms of making connections between feminism and disability, such a politics provides the possibility of learning from our individual differences and utilising this knowledge to enrich feminist and disability politics. Thus we can move beyond separatist strategies while still retaining the strength of identity.

The idea of collectivist politics, in which interdependency and commonality are emphasised, is also suggested by disability theorists. Although Morris (1991-1992) does not utilise Foucauldian theory, her critique of the ways in which binary oppositions are used to define what it means to be a woman with a disability has much in common with postmodern feminist analyses in this area¹⁴. Morris's work is illustrative of the possibilities inherent in the postmodern challenge to the notion of meanings constituted from binary oppositions. Morris's challenge to the ways in which the subject position 'woman with a disability' is produced, centres around the opposition between the *carer* and the

¹⁴ This is discussed in more detail below.

cared for. The polarisation of carer and cared can be destabilised by expanding the definition of caring to include not only physical but emotional labour (Morris, 1991-1992). In proposing this expansion of the definition of the caring relationship Morris reconceptualises caring as a two way process¹⁵. The movement from the terms 'carer' and 'cared for' in favour of the phrase 'the caring relationship' can be regarded as a strategic movement in itself. A subtle change in emphasis from the actions of the individual actors to their inter-relationship has taken place. A rigorous analysis of the role that notions of fixed identity play in constituting the subjectivity of women with disabilities is clearly needed.

This analysis of the role of notions of fixed identity and subjectivity can be found in the essentialism/anti-essentialism debates. The essentialism/anti-essentialism debates are often played out at the site of the body where ideas about what constitutes an identity and how this relates to the groups with which we might identify are discussed in terms of morphology¹⁶. Our bodies act as signs or signifiers of our identity in that they have specific meanings attached to them in the particular moments in which we live. If the pleasures and strengths of shared identities are to be used strategically as we work towards common goals, then it is important that we remain critically self-reflexive and constantly questioning of ourselves and each other. Asking questions about the ways in which particular uses of identity function with regard to others is a critically self-reflexive move. Asking questions such as 'what am I... for her' allows for the place and play of identity without prescribing what the politics of an interaction between feminists and women with disabilities should achieve. Such a politics does not set out to find a moral imperative upon which politics can be based. Rather, the consequences of who we are, what we hope to achieve, and why we might want to achieve it become the focus of political actions. Claiming

¹⁵ For example, in this research Henrietta spoke of 'social working' her carers.

¹⁶ 'The concept of morphology mediates the line between a purely anatomical and a purely psychological account of the body and its pleasures. It denotes the determinacy of the body in the formation of the body or body image. The body's morphology is thus both constitutive of, and constituted by, how it is inscribed, marked, and made meaningful' (Campioni and Grosz, 1983:140-42).

particular identities only becomes divisive if we position ourselves in morally superior places on self-styled hierarchies of political correctness¹⁷.

Disability Politics and the Critique of Essentialism

The strategies of radical feminism are rigorously critiqued by anti-essentialists on the basis of their potential to exacerbate divisions between groups of women. Consciousness raising within radical feminist groups set up an environment in which hierarchies of political correctness or hierarchies of oppression thrived (Guy, Jones, Simpkin, 1990). In such an environment, oppressions such as being a woman, having a disability, being a part of a marginalised culture were owned and revalued. The privileged place in these hierarchies was occupied by the most oppressed. The speech of the most oppressed therefore held the most weight. A similar dynamic is set up in disability texts which talk of the double or triple oppression of women with disabilities. The problem with this position is that it silences people who are not situated near the pinnacle of the hierarchy as it does not legitimate the speech of those who are 'less' oppressed. While it is necessary to acknowledge and revalue identity and difference, it is also necessary to find a politics in which the sense of the argument, rather than the position or identity of the person who makes the argument, determines political strategies of a group.

Adams (1989) advocates a coalition politics in which our allies are best chosen on the basis of their political commitments, not their identities. Identity politics begins from notions of fixed difference, while a coalition politics foregrounds potential commonalities. From this perspective there is a very real place for non-disabled people committed to achieving similar outcomes to people with disabilities. The task of putting feminist or women's issues on the disability agenda, or disability issues on the feminist agenda are places where feminist issues and disability issues might meet. In order to mediate the relations of power and powerlessness inherent in the embodiment of different bodies, identities, and political movements, self-reflexivity is required. Asking the question 'what am I... for her?', is one means by which this self-reflexivity can be achieved. A fluid and flexible politics in which multiple and diverse notions

¹⁷ Political correctness refers to a heightened political consciousness. The views of the politically correct are often regarded as enlightened, 'liberal', morally superior or more correct than those of others who are less 'aware of *the* issues'.

of embodied subjectivity are taken into account is required. Politics that set up hierarchies of oppression and notions such as double and triple disability narrow the focus of political struggle by engendering moral absolutism.

To suggest that the notion of shared identity on the basis of disability should be rejected, is not a claim I imagine women with disabilities would view favourably. Identities, even marginalised identities, are still painful to lose. Women with disabilities are claiming the right to valued identities (see for example, Campling, 1981, Browne, Connors & Stern, 1985, Saxton & Howe, 1987, Stewart, 1989, Lonsdale, 1990, Keith, 1994). Identity can provide the basis from which to make previously unspoken claims. hooks (1989) writes of the feminist focus on 'coming to voice' - as a metaphor for self transformation. hooks suggests that the idea of moving from silence to speech is especially relevant for groups of women who never previously had a public voice. Mercer (1992:433) also writes of the strategic essentialism of black cultural nationalism, or the '...“coming to voice” which transformed the objects of racist ideology into subjects empowered by their own sense of agency...'. 'Speaking becomes both a way to engage in active self transformation and a rite of passage where one moves from being object [Other] to being subject' (hooks, 1989:12). A similar analysis can be applied to the project of destabilising the divisions between non-disabledness as the norm and disability as the Other to this norm.

Gay and lesbian theory also supports the argument for the strategic use of essentialism in disability politics. Fuss (1989:98) argues that, '...adherence to essentialism is a measure of the degree to which a particular social group has been culturally oppressed...'. In this instance she is speaking of lesbian identity. The fact that lesbian theory is less likely than gay male theory to question the notion of a 'lesbian essence' may simply indicate that lesbians have more to lose by failing to subscribe to an essentialist philosophy (Fuss, 1989). On the basis of these insights it would seem there is a place for the strategic use of essentialism in disability theory. The analyses of Fuss (1989), hooks (1989) and Mercer (1992) suggest that essentialist identity categories have their uses and should not be too easily cast aside.

Identity has proved a powerful organising principle for many marginalised groups in society. However, it is argued in this thesis that identity is not the only principle around which a politics of change can be organised.

...The challenge is to go beyond the atomistic and essentialist logic of 'identity politics' in which differences are dealt with only one-at-a-time and which therefore ignores the conflicts and contradictions that arise in the relations within and between the various movements, agents, and actors in contemporary forms of democratic antagonism (Mercer, 1992:425).

A politics that embraces conflicts, differences and contradictions and considers these questions self-reflexively might answer Mercer's challenge. In this study the question of 'what am I... for her?' is forwarded as a principle upon which such political activity might be grounded.

Privileging a disabled identity or claiming multiple minority group status can set the political ball rolling, but another problem with these strategies is the potential they have to fragment political movements into more and more specific groups. This process of fragmentation is potentially profoundly depoliticising. It can be argued that postmodern feminist analyses provide an alternative, allowing us the space to claim multiple subject positions and shared and shifting identities. However, the problem of developing theoretical frameworks with which to destabilise hegemonic discourses remains. Projects such as those proposed by Irigaray have re-introduced the much maligned (within academic postmodern feminist discourse) concept of essentialism. Essentialist and anti-essentialist readings of difference have engendered political strategies which have inspired diverse forms of political action, at different moments in time, with varying degrees of success. The state of the art question for feminism is how we can most productively use essentialist categories in political struggle. In this chapter I have suggested that identities, must be constantly called into question. We need to remain critically self-reflexive, constantly questioning ourselves, and our beliefs, proposing interventions such as the question of 'what am I... for her?', if we are to produce new ways of understanding the world, difference, and disability

Essentialisms have played important roles in political movements. However, we need to move beyond simple deployments of essentialism towards more sophisticated strategies. As previously discussed, postmodern feminist analyses such as the work of Sawicki provide some viable alternatives. Lloyd (1992) provides another alternative. She argues it is possible to avoid minimising disabled identities by employing the radical strategy of *not* starting from a model of 'able-bodied normality' (Lloyd, 1992). Lloyd's strategy of beginning

from the experience of women with disabilities as a way forward for disability culture is a starting point. But what part do people like myself who are non-disabled play in this project? How do we destabilise our own hegemonic positions and learn what it means to occupy the subject position of the other? (Spivak, 1990). I argue that we need to look for a way of speaking through our bodies, that is, of not denying our morphological realities, without slipping into the moral relativism engendered in political strategies that allow hierarchies of oppression to thrive. In such an analysis radical feminism's hierarchies of oppression are avoidable. The task in strategic uses of essentialist categories is to be able to claim certain knowledges on the basis of our embodied differences *and at the same time* retain other bases for our knowledge claims.

Rethinking the Meanings in the Body

I argue that one way in which this strategic use of essentialism might be put into practice is through a rethinking of the body. Postmodern theory suggests that nothing is purely 'natural'. The body within postmodern theory is produced within relations of power through history and culture¹⁸. It can be argued - in the same manner that feminists have argued that man is the privileged signifier and woman is the negated Other - that the body of someone with a disability is known only in relation to the non-disabled body, in that it is the body that deviates from the norm. This section explores the notion of the body as constructed through discourse and the ways in which this impacts upon the politics of identity. In order to present what I consider to be the most relevant postmodern feminist debates in this area it is necessary to turn to Foucault's analysis of the ways in which power works through the body. The following discussion focuses upon two related concepts in Foucauldian theory: 'bio-power' and the notion of 'docile bodies'. In the following section a brief explanation of these concepts is accompanied by a feminist critique of the notion of the docile body and a discussion of the usefulness of Foucault's analysis for the project at hand.

¹⁸ This postmodern conceptualisation of the body is discussed with reference to Foucault's analyses of 'bio-power' and 'docile bodies' below.

Bio-Power

Foucault's conceptualisation of how power works, and his emphasis on the body as a place where the most minute and local social practices are linked with the large scale organisations of power Dreyfus and Rabinow (1982), provide useful frameworks for analysing the lives of women with disabilities. The work of Foucault and feminists who utilise Foucault's work in their analyses, is used to theorise the following discussion.

'Bio-power is the increasing ordering of all realms under the guise of improving the welfare of the individual and the population' (Dreyfus and Rabinow, 1982:xxii). Bio-power works through technologies of power operating on and through the body and the social body. Foucault (1978) suggests that bio-power emerged during the classical age as two separate 'techniques' or 'poles' of power: the control of the body as an organism to be manipulated and the control of the human species. Bio-power is operationalised through these technologies or modalities of power.

The concept of bio-power is useful as it allows us to denaturalise the ways in which a variety of systems such as the medical model and discourses of disclosure affect the lives of people with disabilities. Assessment and classification systems, such as those used by social welfare agencies and other welfare providers that have a major impact upon the lives of people with disabilities, can be understood as techniques of power. For example, people's spending patterns and the way in which they approach paying bills and keeping receipts may be regulated by the requirement that evidence of household expenses are provided for social welfare assessments. Techniques of power may also regulate people's psychological well-being and understandings of themselves. O'Sullivan writes provocatively of her experiences of being graded for the instalment of home aids into her house and of her anxiety over the process. She expresses anxiety at being thought 'a fraud, a malinger. Someone trying to get something for nothing. How will she grade me I wonder? She might think I've got her here under false pretences. Maybe I have. I don't know' (O'Sullivan, 1994:13-14).

A Foucauldian analysis of O'Sullivan's experiences would focus upon systems of classification and the ways in which these discourses work to objectify the subject by the use of dividing practices, in which the subject is either divided

from itself or divided from others (Foucault, 1982). Thus O'Sullivan's uncertainty or collusion in this process of classification ('how will she grade me I wonder?') can be understood in terms of power operating on the body.

Docile Bodies

McNay (1992:41) argues that in emphasising corporeally-centred disciplinary power at the expense of other forms of power '...Foucault simplifies the process through which hegemonic social relations are maintained and also effaces the different types of experiences of individuals in modern society'. McNay argues that Foucault's analysis of power does not account for how women challenge the assumption that they should slip easily and passively into socially prescribed feminine roles, and how material changes in women's lives have been made. The argument that you cannot see reforms to abortion legislation that make abortion more freely available as another means of control over women's lives is used to illustrate this point (McNay, 1992). I agree with McNay's analysis to a point: there is a need to give credit for such changes. However, the issue of abortion could also be used as an example of the ways in which power continues to work through subtle disciplinary practices despite apparent new found freedoms. In New Zealand abortion is still limited and people seeking abortions are subjected to a variety of cross-examinations.

Taking McNay's critique as a starting point and analysing the issue of abortion in terms of Foucault's ideas around confessional discourses, the apparent freedoms women have gained in this area can be understood in a different light. In order to obtain a legal abortion disclosure of a variety of information including sexual, psychological, medical and economic is required. Foucault (1978:61-62) suggests that:

The confession is a ritual of discourse in which the speaking subject is also the subject of the statement; it is also a ritual that unfolds within a power relationship, for one does not confess without the presence (or virtual presence) of a partner who is not simply the interlocutor but the authority who requires the confession, prescribes and appreciates it, and intervenes in order to judge, punish, forgive, console and reconcile...

In terms of the power and knowledge as it is conceptualised within the confessional ritual, the gains women have won in this area come at a high price. Gaining freedom from pregnancy comes at the cost of increasing power of medical discourse. The power of confessional rituals - such as O'Sullivan's submission to grading and women's submission to pregnancy counsellors and medical professionals - lies in the promise of liberation or absolution. The tacit understanding is that by revealing our deepest secrets and desires we will be liberated (Dreyfus and Rabinow, 1982). Foucault (1978:159) suggests that 'the irony of this deployment is in having us believe that our "liberation" is in the balance'. The irony Foucault speaks of is that these revelations are a part of the various technologies of power. Foucault is suggesting that in the present day power works in more subtle ways than it did in the past. Prisons for example have replaced the gallows¹⁹.

This analysis of bio-power and the notion of docile bodies can be linked to experiences of deinstitutionalisation and community living in Aotearoa/New Zealand. Utilising Foucault's (1978) analysis to address this issue, it can be argued that although community living is now widely regarded as superior to institutional living it should not be accepted uncritically. Power is still being exercised, in the lives of people who live outside of institutions (Foucault, 1982). A Foucauldian analysis would suggest that power now operates in more subtle ways: the technologies or modalities of power have changed. Confessional discourses and systems of grading and classification have replaced the rules and routines of the institution.

Foucault, Disability and the Body

A Foucauldian analysis allows us to approach issues of sexual difference, power, and domination in a manner that considers the ways in which power differently constitutes particular kinds of bodies and allows them to perform particular kinds of tasks, thus constructing specific kinds of subjects (Gatens, 1992). Gatens (1992:127) suggests that gender '...is a material effect of the way in which power takes hold of the body rather than a ideological effect of the way power 'conditions' the mind'. This analysis can be applied to the bodies of people with disabilities. The ways in which the bodies of people with disabilities

¹⁹ See Turner, Bryan S. (1991), cited in bibliography, for a detailed discussion of Foucault's analysis of the workings of power.

are intruded upon and disciplined make the workings of power all the more observable. Munford (1992) writes of the myriad of ways in which the bodies of people with intellectual disabilities are assessed, classified and ranked. It is proposed in this study that, subjectivities are formed by the workings of power on the body and that an examination of the construction of the notion of subjectivity has the potential to engender powerful resistant discourses for people with disabilities. These ideas are discussed below in the context of postmodern analyses of the experience of disability. These analyses consider the ways in which the notion of 'disability' is produced through the workings of a variety of discourses.

Liggert (1988), Munford (1990, 1992), and Kerr (1996), bring a Foucauldian perspective to disability politics. Munford and Kerr's analyses are concerned with the workings of power on the body while Liggert is concerned with more general issues associated with discourse and subjectivity. Liggert and Munford include critiques of forms of disability politics based on liberal humanist philosophies. Munford talks of the ways in which the liberal philosophy of normalisation²⁰ can be used to force people with intellectual disabilities to adapt and fit into mainstream society without acknowledging the material restrictions on their lives. She makes the point that, the concept of normalisation as it is used above is not the same concept to which Foucault is referring. However, his particular use of the term has relevance for people with disabilities (Munford, 1990, 1992) in that the concept of normalisation²¹ can function to mask the diverse and multiple subject positions people with disabilities may occupy.

Foucault (1995) suggests that the mechanisms of normalisation are multiple and wide ranging. In Liggert's (1988) analysis the normalising functions of interest group politics are called into question. Liggert suggests that interest group politics function to normalise the subjectivity of people with disabilities by masking the diversity of the disabled subject. Liggert offers an analysis of the ways in which power works to produce disabled subjects. She suggests that

²⁰ The normalisation principle is a popular liberal strategy for change and is closely associated with the concept of community care which is currently popular in New Zealand. However, Browne and Smith (1990) suggest that the seemingly progressive changes allowed under normalisation policies are in fact merely cosmetic: people with disabilities are still marginalised.

²¹ In the sense that it is used in (20) above.

people with disabilities can only speak the truth of themselves from the position of a person with a disability:

...In order to participate in their own management disabled people have had to participate as disabled. Even among the politically active, the price of being heard is understanding that it is the disabled who are speaking (Liggert, 1988:273).

In terms of the essentialism/anti-essentialism debates discussed in this chapter Liggert's strategy could be read as an anti-essentialist move. However, Liggert's (1988:274) analysis is more complex than this. She suggests that 'relentless refusals to go along with what appears to come naturally are the front-line battles in the politics of disability'. Liggert's political strategies can be theorised using Foucault's notion of resistance²². Refusal to go along with what comes naturally involves an identification of and subsequent resistance to the workings of power. The front line battles in the politics of disability begin from the experience of disability and utilise this experience to argue against practices of marginalisation.

Conclusion

Whether there is some essential starting point for this process, or whether as anti-essentialists argue there is no prediscursive self and our bodies are but blank slates, we cannot deny that meanings are attached to our corporeal specificities and that power works through these meanings. Kirby (1991) argues that the category 'woman' cannot be thought of as a catachresis (a wrong name, or a name with no literal referent):

This wrong name, although not a proper name, is never immaterial. For if women matter at all, it is as this word's embodied realization (Kirby, 1991:17).

Our bodies and how they function cannot be denied. To have the body of a woman, a woman of colour, a woman with a disability, has a specific meaning at this particular moment in time. Similarities as well as differences are

²² A detailed analysis of the notion of resistance and its relevance to this study is offered in Chapter Two.

attributed to these different bodies. The strategic use of essentialism allows us to put these meanings to work, making claims based on sameness and difference according to our needs in a particular postmodern moment.

We can learn a lot about ourselves from studying others. In this study it is argued that the bodies, lives and theories of women with disabilities can illuminate aspects of feminist analysis. For example, how does the myth of the perfect body impact upon women's lives? Women with disabilities have much to say about issues such as this. This study can be regarded as an indicator that feminism is beginning to listen.

This chapter has provided a postmodern feminist analysis of the ways in which disabledness and non-disabledness are constituted within relations of power. Destabilising the notion of fixed and stable identities and using these understandings to deconstruct distinctions between non-disabledness as the norm and disability as Other, are major tasks in this study. Asking the question of 'what am I... for her?', finding out *what we might be for one another*, and moving towards shared and shifting alliances, is a major aim of this study. Problematizing the connection between our ontological realities, who we are, and our epistemological understandings, what we know, provides the space for an alternative exploration of knowledge and how we come to know. I argue that we can make claims based on ontological realities and argue points on the basis of our lived realities without who we are becoming what we know.

The exploration of alternative conceptualisations of the concept of identity begun in this chapter is continued in Chapter Two. Chapter Two explores the idea of the self as a constituent of communities and the implications this has for creating dialogues between feminism and disability politics. The destabilisation of the notion of identity as a fixed, stable and definable entity develops into a questioning of myself in relation to herself, or the question of 'what am I... for her?'. .

Chapter Two

Between Selves and Communities

Introduction

In this chapter I look at the political potential postmodern theories of ‘the self’ - ‘crafting the self’, ‘thinking through the self’, ‘the care of the self’ - have for the project of creating dialogues between feminism and disability politics. An exploration of the concept of ‘selves’ as constituents of communities is an important aspect of this discussion. The split between the autonomous individual and the community is called into question through a discussion of the self as a constituent of communities. The potential this train of theoretical analysis has for feminism and disability politics on a practical level, conceptualised in the question of ‘what am I... for her?’, is a guiding principle throughout this thesis.

Postmodern thought facilitates the following discussion of the self. The theoretical discussion of the construction of selves within relations of power is important in this thesis. I argue that an analysis of selves within relations of power provides the theoretical basis from which to develop a method that encourages productive dialogues between feminism and disability. Ideas about authorship and authority are discussed within the context of debates about the death of the subject. The agency/structure debates provide a background for a discussion of theories of the self. The relevance of the concept of the self to the question of creating dialogues between feminism and women with disabilities is also introduced. These ideas are relevant to the development of a method that seeks to avoid appropriative practices (in this case speaking for the research participants).

‘The subject’, ‘the death of the subject’, the ‘subject reborn’: what do these phrases mean? Why are they important in postmodern feminist theory? and why are they important in this chapter? Analyses of the ‘death of the subject’ are critiqued on the basis that they leave no space for the agency of the individual. Postmodernism’s answer to this is a critical reading through the self where we understand that we are discursively created and that we have the capacity to resist the discourses that surround us. Thus, the self and a critical self-conscious analysis of the ways in which selves are crafted become central in postmodern politics.

Questions about how ‘selves’ are created are a topic that has received attention in feminist theory. The essentialism/anti-essentialism debates discussed in Chapter One provided some background to the ways in which this topic is

approached below. The postmodern critique of binary constructions of meaning begun in Chapter One continues throughout this chapter. However, in this chapter the agency/structure debate stimulates this discussion. The limits of human agency within the agency/structure debates, illustrate the relevance of the postmodern critique of binarism to conceptualisations of disabledness and non-disabledness. This analysis sets the scene for a discussion of the concept of 'the limits' and the possibilities and political opportunities beyond the limits of what is known.

Contradiction and discontinuity are integral in postmodern analyses and this is reflected in the various analyses I draw upon in this chapter. Postmodernisms' major challenge in this theoretical terrain is its challenge to the binary structure of the ways in which meanings are constructed. In postmodern theory the subject is discursively created by a plethora of competing discourses. Postmodern theories focus on how discourses such as biological and ethnic categories, nature and human nature function in society, rather than on determining an order of ascendancy. The death of the subject and the agency/structure debates relate to the central question in this thesis: the maintenance of divisions between non-disabledness as hegemonic and disability as Other. The ways in which the death of the subject impacts upon the place 'I', as the author or authority in this study, occupy in relation to the research participants, is also discussed in this chapter.

Postmodernism allows us to ask questions about the ways in which categories and labels function to legitimate and perpetuate certain forms of power. We can therefore question the legitimacy of these systems of classification. A postmodern framework allows us to ask a variety of questions. For example, can we talk of 'women' or 'disability' or can these more productively be thought of as 'fictions', creations, that exist only in our minds? How did these categories become naturalised? and why do we not question these seemingly natural categories? How do conceptualisations of 'woman' or 'disability' function in relation to the fashioning of the self? And, if we are going to question and destabilise these categories in the name of valuing 'diversity' and 'difference', do we run the risk that politics will disintegrate into individuated nothingness, the self, pure and unmitigated, a self who is unable to even think of collectivism? Is resistance possible if we are so thoroughly discursively saturated that nothing exists outside of discourse? These issues are central in feminist conceptualisations of the postmodern subject and are an important aspect of the construction of this chapter.

The Death of the Subject

The subject in question is the self-conscious, knowing individual of modernist thought. The subject is imbued with attributes such as agency, action, autonomous thought and authorship. Postmodernism challenges this conceptualisation of the subject. However, questioning that *man* (sic) can be an objective, knowing subject, capable of autonomous, original thought is not new, nor is it limited only to postmodern thought. Philosophers since Plato have questioned autonomy of thought. The death of the subject has been much talked about in the work of a number of theorists including, Michel Foucault, Jacques Lacan¹, Roland Barthes², Claude Levi-Strauss, Jean-Francois Lyotard³ Julia Kristeva and Luce Irigaray. Within postmodernism the humanist conceptualisation of the subject is called into question. This calling into question of the humanist subject within a postmodern framework is the subject of the following section.

The engagement of postmodernism with the notion of the death of the subject is of particular interest in this project because for those outside the privileged subject position of the rational, autonomous, objective, knowing subject, those who fail to fulfil the criteria necessary to be acknowledged as the master subject - such as women and people with disabilities - this critique opens up exciting possibilities. The critique of the authority of the subject opens up a discursive space in which previously marginalised subjectivities, those who have been assigned the category of Other, can make legitimate claims.

Yeatman (1994) writes of the integrity of the masculine subject and women's position as Other. Yeatman contends that in comparison to the integrity of the master subject women's identity still appears '...just as the master subject has always said - as a lack (lack of maturity, lack of development in respect of the higher levels of social and ethical life)' (Yeatman, 1994:30). A feminist politics in which there is an insistence on the discursive construction of selves as always

¹ Lacan conceptualised a decentred subject in the unconscious.

² Barthes proposed death of the author suggesting that it is the subject that speaks not the author.

³ Lyotard spoke of the decentred self. For Lyotard the self can never be the author of meaning. This repudiation of the traditional notion of the self is a result of the linguistic notion of the self as already presented as part of the social bond, as always a function of language.

already inscribed by, and never outside of, power relations allows a radical calling into question of how knowledge is produced and legitimated; that is, of how we come to know. Within such a framework the maturity and ethical development of the master subject becomes merely one legitimating strategy, or knowledge claim, among many. Oppositional political affiliations in which braidings of various and multiple selves combine to challenge the hegemony of the master subject unfold. Like the identity and difference debates discussed in the previous chapter, working with the literature on the death of the subject allows an exploration of the epistemological bases of oppositional politics.

In the previous paragraph I traced the liberatory potential of the abandonment of the subject within a postmodern framework, outlining an opening of discursive spaces for resistance and a privileging of difference. However, the problems inherent in proposing the death of the subject have been cautioned against repeatedly, on the basis that doing away with the notion of the subject removes from under our feet the moral ground on which we make choices, and organise politically. In other words it engenders a slide into nihilism or moral relativism.

Feminist critiques of the potential nihilism inherent in postmodern theory are wide ranging. I have chosen to engage with the question of the ground upon which we make knowledge claims via Yeatman's (1994) critique of an article by Mohanty (1989), because Yeatman's analysis of the popularly debated ethical dilemma is succinct, erudite and practical. Yeatman addresses the problems of nihilism and relativism in postmodern analysis through a politically engaged analysis directly relevant to the central concerns of this study, that is, the question of negotiating alliances between differently positioned social actors. Yeatman's analysis of the bases upon which we make knowledge claims is relevant to the question of how we might create dialogues and negotiate alliances between feminism and disability. Working with Mohanty's article, Yeatman explores questions of subjectivity. An outline of Yeatman's critique follows.

Yeatman's critique centres on the question of the necessity of retaining the concept of a universal subject. The validation of plurality over commonality - and the potential this has to legitimate moral irresponsibility - has been identified as the ethical paradox of postmodernism (Soper, 1990). Placing this paradox in a historical context, Mohanty (1989:13) asks, 'could we, in other words, really afford to have *entirely* different histories, to see ourselves as living - and having lived - in entirely heterogeneous and discrete places'. In

Mohanty's analysis, positing this minimal commonality between 'us' and 'them' grounds the capacity to act purposefully, to be capable of agency and basic rationality, all of which it can be argued are necessary to an emancipatory politics.

Yeatman agrees that the sharing of a minimal common ground is the condition of respect for, and understanding of, struggles for emancipation different from our own. She also agrees that a privileging of pluralism inhibits the commonalities of different struggles. However, she does not agree that a reinstatement of a universal subject of human agency or a return to Soper's (1990) universal, transcultural sensibility is necessary or desirable.

Yeatman's theorising is founded on a conceptualisation of postmodernism that recognises an indebtedness to modernism and an acceptance of the basic significance of the principles it proposes to go beyond. She argues that postmodern emancipatory movements mobilise their own historically specific constructions of minimal commonality; that is, postmodern emancipatory politics are strictly pragmatic. Legitimate connections (with those whose struggles for emancipation are different from our own) have to arise out of negotiated agreements constructed by the coming together of differently positioned social actors (Yeatman, 1994).

Negotiating agreements between people whose struggles are different from our own is one of the principles upon which this study is founded. The previous chapter approached this problem through an analysis of embodied difference. It was argued that, while it is necessary to take embodied differences into account, this does not preclude the possibility of retaining shared political goals. Approached from the perspective of achieving shared political goals postmodernism can provide the space for practical, politically viable solutions. In terms of providing a viable theoretical basis for this study, part of the attraction of postmodern emancipatory politics lies in this privileging of *pragmatism*. Rather than one revolutionary goal that must be achieved in order to become emancipated, emancipation is conceptualised as an ongoing process. Contestations occur on an everyday basis and on the basis of the everyday.

Nothing, even good intentions, can be conceptualised as outside of power relations (Yeatman, 1994). If there is, as postmodern analyses suggest, no longer an absolute, universal conception of truth and justice then:

the transparency of good intentions guarantees nothing, and the ideal of transparency is a dangerous illusion, encouraging as it does, various forms of moral terrorism practised on self and others. Instead, good intentions are always in the service to a particular discursive regime... (Yeatman, 1994:7).

Good intentions are unlikely to be the target of challenge. It can be argued that this makes good intentions a particularly important site for contestation. For example, I am sure the introduction of characters with disabilities on Shortland Street (a popular prime-time soap opera) was done with the best of intentions. But why are portrayals of characters with disabilities so often heterosexual, middle class men in wheelchairs and why are regular characters with ordinary jobs for whom disability is a side issue rather than the focus not included in this drama? Having a disability can be regarded as the primary function of these characters. If the problem of representation is linked to the idea that people with disabilities are too often asked to speak about disability or make disability the focus of their lives, then good intentions can be seen to be part of the process by which people with disabilities continue to be regarded as Other. Do we need an *absolute, universal* conception of truth and justice to ground a moral response to these questions?

Foucault (whose work influences many of the authors cited in this chapter) would give a negative response to this question. Foucault believes 'there is no sovereign, founding subject, a universal form of subject to be found everywhere' (Foucault 1988:50). Foucault answers the critique that any political program must be grounded in an absolute, universal conception of truth and justice, with the notion of local and specific struggle. The stable foundational certainties of modernist political struggles are called into question. The idea of the revolutionary subject struggling towards a singular common goal gives way to the notion of localised resistance. Postmodern strategies legitimate local political affiliations. According to Yeatman (1994), the Utopian aspect of postmodern imaginaries of self determination lies in the visionary aspect of particular everyday struggles for social change. However, this does not preclude an emancipatory consciousness of seeking to build connections between the various struggles for self determination, explorations of affinities, or acknowledgement of differences (Yeatman, 1994). Using disability as a focus for innovation in women's studies is one way in which such connections might be built (Matthews and Thompson, 1993) .

Another aspect of the theorising around the death of the subject relevant to this project is the potential it carries to challenge the idea of original thought, and the author. Problematising the authority of the author, and the power the researcher exercises in the construction of a research project are central issues in this thesis⁴. This calling into question of authority arises amidst the exasperation of women and people with disabilities, who are not content to be positioned as the 'objects' rather than the 'subjects' of research. The critique of the death of the subject-that the ensuing lack of agency accorded to the subject leads to an over-emphasis on the role of social structures-has generated a body of knowledge on the 'rebirth of the subject', or 'the subject reborn'. Rather than a return to modernist or humanist conceptualisations of the subject, this rebirth of the subject is centred around a rethinking through the self, or, in the words of Foucault, 'a critical ontology of ourselves'. This 'critical ontology of ourselves', is a critique rooted in an endless questioning of power and the mechanisms of repression (Heckman, 1990:183). Foucault's opposition to the subject of humanist thought with its universalising and hence subjugating tendencies (Heckman, 1990, McNay, 1992) is important in this project. For example, under this critical ontology of ourselves the processes by which research objectifies the research participants can be problematised⁵. By questioning 'what am I... for her?', the role I, as the non-disabled feminist researcher, play in maintaining the divisions between non-disabledness as the norm, and disability as the Other, can be called into question.

This calling into question of the epistemological basis of modernist thought inherent in the problematisation of the subject is also of interest in feminist and disability politics as it carries with it the potential to challenge the inherent masculinity and ablebodiedness upon which subjectivity is founded. The gendered assumptions upon which politics proposing a universalised revolutionary theory rest can be called into question. The gendered, raced, classed, ableist (to name a few) hierarchies under which they operate can be challenged. As an example, rationality and objectivity are privileged over emotionality as political constructs. Rationality and objectivity are masculinised and equated with power while emotionality is feminised and marginalised. The decentring of the gendered subject and a new critical thinking through the self, or, selves, allows a deconstruction of the categories defined as masculine and feminine, a critique of the hierarchical ordering of masculinity and femininity,

⁴ See the discussion of the feminism and science debates discussed in Chapter Three.

⁵ See Chapter Three for a detailed discussion of this.

and the possibility to challenge hegemonic world views on the basis of the knowledges of previously subjugated others.

In this section we have gone from the death of the subject, through a critique of the lack of agency the subject's death engenders, to the rebirth of the subject through a critical ontology of ourselves. This critical ontology of ourselves is an emancipatory project. A project of emancipation implies a degree of agency, an ability to 'free' ourselves from bonds. Disagreements over the degree to which agency and structure influence our potential for emancipation have generated wide ranging debates. As well as being important in terms of the current analyses of the subject and the self, the agency/structure debates illustrate the problems inherent in a system of logic founded on binary oppositions. Defining agency (with its connotations of autonomy) in opposition to structure (behavioural responses to environmental stimulus, or lack of autonomy) denies the inter-relation between these two concepts.

Agency/Structure

Why are agency and structure as they relate to the notion of the subject important in this discussion of the self? Haber (1994:9) provides part of the answer to this question:

All political theories begin from assumptions about the nature of the person and society. A political theory will be judged useful or true or convincing to the extent to which it matches one's background beliefs regarding the quiddity and parameter⁶ of the self and society.

Structuralists might argue that we can be regarded as conduits, upon and through which culture channels itself. However, if - as a postmodern perspective would suggest - this is not the case, how does the self come into being? To the extent that agency and structure are tied to our assumptions and our belief systems about self and society, they affect our beliefs about the degree to which we are socially or biologically constructed; the ways in which we choose between

⁶ Quiddity refers to the ways in which we conceptualise, or understand, the essence of a person. The 'parameter of the self and society' refers to our understandings of the boundaries between the self and society. These ideas are explored below through an engagement with Haber's conceptualisation of the-subject-in-community.

various theories and belief systems; and the ways in which we conceptualise categories like ‘the personal’ and ‘the social’.

Agency and structure are pivotal in discussions of the subject. The debate over agency and structure and the role of the subject do not have their inception in postmodern thought.⁷ Debates over the subject often cross boundaries between modernist and postmodernist thought, and the definition of what constitutes agency varies according to the paradigm within which it is conceptualised. Agency in modernist terms is tied to the notion of the autonomous rational knowing subject. As a corollary it is often argued that we do not have agency without some notion of a fixed and stable essence. However, the idea that human agency is contingent upon the notion of a unitary subject is refuted in postmodern analyses on the basis that it does not account for the multiplicity and diversity in people’s lives.

As Yeatman’s (1994) critique of Mohanty’s (1989) article discussed earlier in this chapter demonstrates, the notion of a stable unitary subject is not a necessary prerequisite for collectivised emancipatory struggle. It is possible to imagine that alliances between differently positioned political actors can be negotiated without recourse to the notion of a fixed and stable subject. In a project designed to make links between feminism and disability politics the idea that there is one objective, rational, authoritative, subject position is potentially divisive. The postmodern conceptualisation of the self, discussed below, provides an alternative to the notion of the unified subject. The central question around which this study is structured, that is, ‘what am I... for her’, is grounded in this postmodern conceptualisation of the self.

From the Unified Subject to the Self

In postmodernist thought agency and structure are eclipsed by the idea of discursive construction, the idea that we are discursively constructed subjects, or subjects produced by a plethora of competing discourses.⁸ Rather than being

⁷The idea of agency and structure is linked to critiques of the Marxist model of the base and the superstructure where ideological factors are subsumed to the overarching influence of the economic base. Within a Marxist framework our subjectivity is contingent upon economic factors which themselves determine the ideological.

⁸Postmodernism challenges not only the binary nature of the agency/structure debate but also language and conceptualisations of the self constructed on the basis of binaries such as man/woman, ability/disability. In challenging binarism and fostering an ‘and-both’

concerned with the precise degree of agency or structure at work in each instance, postmodernism could be regarded as a gateway between which these various ideas flow. Postmodernism rejects the dichotomy between the transcendental (essentialised, prediscursive) subject and the wholly constituted subject (Heckman, 1990). The subject is ‘... an entity that is constituted by discourses but is also capable of resistance to that constitution. It is a subject that can resist its subjugation and attempt to fashion new modes of subjectivity’ (Heckman, 1990:189). Haraway (1988) offers a vision of the opportunities that arise when we problematise and move beyond the notion of the unified subject. Haraway (1988:585-586) writes:

The boys in the human sciences have called this doubt about self-presence the ‘death of the subject’ defined as a single ordering point of will and consciousness. That judgement seems bizarre to me. I prefer to call this doubt the opening of nonisomorphic subjects, agents, and territories of stories unimaginable from the vantage point of the cyclopaedian, self-satiated eye of the master subject.

Haraway argues for partiality, objectivity, boundary crossing, and situated knowledges. She offers a different way to think about how we think, come to know, and make choices.

It can be argued that it is the privileging of partiality and situated knowledges in the conceptualisation of the subject that holds the potential for feminism and disability politics. The ‘self-satiated eye of the master subject’, male and master(ful), is called into question. It is the gendered and subjugating nature of the subject conceptualised as a single ordering point around which knowledge is organised that feminism calls into question. A major concern in this study is to consider how theories which have grown since the positing of the death of the subject might be read through the lenses of feminism and disability theorised as tandem discourses. This question is considered in more depth in Chapter Seven.

perspective, postmodernism would argue for both agency and structure. Agency and structure both come into play in the crafting of selves to varying degrees in various circumstances, the limits and pervasiveness of which cannot be fixed.

The Self

The subject died and was reborn in a new guise. Feminist postmodern theory has moved along and around the sticky subjects of authority, truth, knowledge and rationality. Retaining the enlightenment⁹ hope for a more just society while rejecting absolutes, totalising and universalising theories, is a central question in this theoretical terrain. However, the question of the role of - and limits on - human agency in the quest to destabilise hegemonic discourses, remains. It is out of this theorising around subjectivity that the body of knowledge on *the self* or *selves* has arisen. The following section on the self draws heavily from the work of feminists who have engaged with Foucault and from Foucault himself.

Foucault's work is often critiqued by feminists for the lack of agency afforded to the human subject. McNay, (1992), talks of a lack of scope for individuality and personal experience. McNay critiques Foucault's earlier work in which the body plays a central role, arguing that a major 'problem with Foucault's notion of the body is that it is conceived essentially as a passive entity upon which power stamps its own images' (1992:12). McNay is speaking of Foucault's 'docile bodies'.

Turning to the work of Foucault it is evident that this is a fair critique. For example, in 'Discipline and Punish' Foucault (1995:138) argues that:

...Discipline produces subjected and practised bodies, 'docile' bodies. Discipline increases the forces of the body (in economic terms of utility) and diminishes these same forces (in political terms of obedience). In short, it dissociates power from the body; on the one hand it turns it into an 'aptitude', a 'capacity', which it seeks to increase; on the other hand, it reverses the course of the energy, the

⁹Foucault rejects humanism but not the Enlightenment itself. 'In any case, I think that just as we must free ourselves from the intellectual blackmail of being "for or against the Enlightenment," we must escape from the historical and moral confusionism that mixes the theme of humanism with the question of the Enlightenment' (Foucault, 1984:45). Heckman (1990:183), sheds some light on Foucault's scepticism, suggesting that the Enlightenment was a call to critique as opposed to humanism's universalising and hence subjugating tendencies. Foucault's critical ontology of ourselves, and the related concepts of 'the self' and 'the limits' discussed further on in this chapter, relate to Foucault's engagement with Enlightenment thought.

power that might result from it, and turns it into a relation of strict subjection .

However, in his later work Foucault addresses the problem of limited agency with the introduction of an 'ethics of the self'. Foucault spoke of his insistence on:

techniques of domination... [and] the importance of talking about "other types of techniques", above all 'techniques which permit individuals to effect a certain number of operations on their own bodies, on their souls, on their own thoughts, on their own conduct and this in a manner so as to transform themselves, modify themselves, or to act in a certain state of perfection, of happiness, of purity, of supernatural power, and so on' (Foucault, 1980,¹⁰ in Miller, 1993:321-322).

He also indicates that he is interested:

... in the way in which the subject constitutes himself in an active fashion, by the practices of self, these practices are nevertheless not something that the individual invents by himself. They are patterns that he finds in his culture and which are proposed, suggested and imposed on him by his culture, his society and his social group (Foucault, 1988b:11).

In contrast to the straightforward causal connection between social structure and the individual inherent in the notion of docile bodies, Foucault proposes, in his later work, a dynamic relationship between agency and social structure (McNay 1992).¹¹ However, the issue of how the subject moves outside of the patterns suggested or imposed by the workings of society and social structure remains (McNay, 1992). Foucault would suggest that we achieve this through the process of 'resistance'. Foucault (1978:95) writes, 'where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power'. Foucault links power and resistance claiming that liberation is achieved through a plurality of resistances. Foucault's

¹⁰ From a tape and transcript of the Howison Lectures, University of California, Berkeley, 1980.

¹¹ Rather than a radical contrast to his earlier work the introduction of the self builds upon Foucault's analysis of the body.

notion of resistance to power has been analysed by a number of feminist theorists (see for example, Weedon, 1987, Heckman, 1990, Kondo, 1990, Sawicki, 1991, Yeatman, 1994). However, contention exists over the potential of resistance as a viable political strategy (McNay, 1992, Haber, 1994).

The rebirthing of the subject through the self with its proposal of multiple sites of resistance to power is of interest for feminism and disability politics. The legitimating strategies of meta-narratives such as 'justice', 'equality', and 'the level playing field' - often used to legitimate relations of domination - can be challenged. If we consider that such meta-narratives are constructed in the service of particular outcomes, and that these outcomes disadvantage women or people with disabilities thus contributing to experiences of marginalisation, then we have grounds to challenge the salience or naturalness of these meta-narratives.

Using his historical method of archaeology and later genealogy¹² Foucault was concerned to expose the underpinning of naturalised discourses and thus destabilise hegemonic subject positions. In Volumes Two (1986) and Three (1988a) of 'The History of Sexuality' Foucault offers an historical analysis of the means by which we might come to understand how subjectivity is constituted through practices of the self. This interest in the self is not a return to the idea of the unitary, founding, naturalised subject. Rather, it could be understood as a recognition of both the interaction of, and the discontinuity between, the agency of the individual, and structural practices. The subject is reborn in a non-essentialised form.¹³

Postmodernism's eschewal of meta-narratives is a site at which charges of relativism or liberal pluralism¹⁴ are often laid. The study of the self is a site at

¹² Archaeology and genealogy are two approaches utilised by Foucault. Archaeology refers to analyses of systems of knowledge. Concentrating on what has been discounted or excluded as knowledge Foucault conceptualises history as a discontinuous rather than a teleological process. With an archaeological approach Foucault is 'concerned to describe the historical presuppositions of a given system of thought, along with the forms of exclusion or limitation they establish in regard to what may be said or done' (Patton, 1987:226). Genealogy utilises analyses of modalities or technologies of power to display the underlying plural and discontinuous origins of culture, their historical specificity and the ways in which they can be transformed by changes in external forces (Patton, 1987). Foucault sometimes utilises both approaches in a single study (Patton, 1987).

¹³ See Chapter One for a discussion of the concept of essentialism.

¹⁴ Liberal pluralism refers to a situation where all forms of behaviour are seen to be equally valid regardless of the consequences of that behaviour. Liberal pluralism is critiqued on the

which these charges are played out. These charges call into question the moral grounds upon which we make decisions. Rather than promoting relativism or unmediated pluralism, this movement away from meta-narratives as legitimising strategies offers us a code of ethics rooted in our understanding of day-to-day specific and local realities.

It is not unreasonable to suggest that this movement to the local and specific, this de-essentialising of the self, understanding the self as multiple, contingent, chimerical, unstable and momentary; might result in a fracturing of consciousness, or an inability to find a basis from which to make claims. However, feminism does not content itself with critique. Feminism's critical collusion in the deconstruction of the authorial 'I'¹⁵ is an undertaking that constantly foregrounds a basic tenet of feminism - community. The conceptualisation of the self as both contingent upon, and constituted by, community and others can be considered as one of postmodernisms purely pragmatic gestures. The practicality of a community oriented conceptualisation of the self as it relates to the possibility of meddling with and destabilising existing social relations is demonstrated in the analysis of Weeks (1985) below.

Offering a community oriented alternative to the numerous charges of unmediated pluralism regularly levelled at postmodernism,¹⁶ Weeks (1985:242) (a theorist of sexual politics interested in the work of Foucault) proposes a radical pluralism that is: 'sensitive to the workings of power, alive to the struggles needed to change the existing social relations which constrain sexual autonomy, and based on the "collective self-activity" of those oppressed by the dominant sexual order'. Like Foucault, Weeks proposes a morality rooted in localised realities and a privileging of human diversity. Utilising Foucault's analysis we can study, unpack and denaturalise the everyday to find the grounds for moral theory and privileging of one discourse above another. The potential this strategy has to provide opportunities for resistance to practices of marginalisation is discussed below.

basis that it is impossible to think through values and make distinctions. This point is often debated around the problem of privileging one discourse over another (or relativism).

¹⁵ For more information on the deconstruction of the authorial 'I', see Trinh (1989:9) and Chapter Nine in this thesis.

¹⁶ This ethical paradox of postmodernism is discussed with regard to the question of negotiating alliances between differently constituted social actors in the section on the death of the subject above.

Resistance

The need to find an alternative basis for a politics rooted in an anti-essentialist understanding of the self is not the only area in which morality comes to the fore. With the introduction of ‘an ethics of the self’ into Foucault’s work morality becomes an important issue in terms of its relationship to the concept of resistance. A distinction is made between morality understood as:

... a set of values and rules of action that are recommended to individuals through the intermediary of various prescriptive agencies such as the family (in one of its roles), educational institutions, churches, and so forth.

and morality as:

... the real behaviour of individuals in relation to the rules and values that are recommended to them: the word thus designates the manner in which they comply more or less fully with a standard of conduct, the manner in which they obey or resist an interdiction or a prescription; the manner in which they respect or disregard a set of values (Foucault, 1986:25).

According to McNay, ‘it is these different practices, ranging from the concrete processes of ordering one’s day-to-day existence to the spiritual significance that one attaches to one’s activities, that Foucault understands as the ways in which individuals give meaning to their activities and seek to interpret their experiences’ (McNay, 1992:52). This idea of rooting politics in an analysis of day-to-day practices is an integral component of the method utilised in this study. It can be argued that we can look at the process by which certain subjectivities become marginalised and search for ways to legitimate and denaturalise marginalised subject positions such as woman or woman with a disability.

The idea that resistant discourses have their inception in the micro-processes of everyday life is familiar in feminist writings. Feminist texts such as those of Irigaray (1977), Moi (1985), and Kondo (1990), discussed below, articulate a variety of sites at which opportunities for resistance exist. In common with Foucault, the idea of challenging the binaries on which our ideas of what it is

possible to know rest is strategic in the process of resistance suggested by these authors.

In 'This Sex Which is Not One' Irigaray (1977) poses an alternative conceptualisation of what it might mean to be a woman. Her analysis is grounded in a challenge to the notion of binary constructions of meanings. Irigaray's purpose is to disrupt patriarchal logic through the use of mimeticism, or the mimicry of male discourse (Moi, 1985). Her method involves directing women to look to our morphology as a means of interpellating¹⁷ definitions of the female self. Her description of a threshold of 'mucosity', rooted in the morphology of feminine lips that are strangers to dichotomy, directs us to look to alternative strategies and hints at possibilities for discourses of resistance beyond those we think or know. The idea of mucosity suggests fluidity of strategies combined with strong viscosity of purpose.

It is at this point, where Irigaray's prose touches directly upon the body, that her analysis meets with charges of essentialism. However, Irigaray (1977) uses her analogy of the lips of feminine morphology ironically, casting phallogocentric discourses of femininity back upon themselves to the point where the stereotypes explode. Moi's (1985) interpretation of Irigaray's work is brought to this discussion in order to make it more comprehensible. By demonstrating the ways in which irony was and is a powerful tool in the hands of women, Moi's analysis makes Irigaray's work understandable on a practical level. While Irigaray herself hints at the uses of irony and memesis in her analysis of women's lives, her analysis is not carried out at a level that makes it particularly accessible to an uninitiated reader. Positioned as I am away from the context of French feminist and philosophical thought I bring a particular interpretation to Irigaray's work.

Taking the phallogocentric discourse of women's embeddedness in her biology to the extreme of the lips of the vagina and the lips of the mouth speaking together, Irigaray (1977) seeks to undo the effects of this discourse simply by overdoing it (Moi, 1985). Moi, (1985:140) suggests that Irigaray's analysis is anti-essentialist in that it explodes the myth of biological determinism by taking '...what is in any case an ineluctable mimicry...' and doubling '..it back on itself, thus raising the parasitism to the second power'. Irigaray's mimicry is a conscious acting out

¹⁷ In postmodern feminist discourse interpellation suggests the questioning, disruption or challenging of hegemonic or naturalised discourses.

of the mimetic, or hysteric, position allocated to all women under patriarchy (Moi, 1985). As demonstrated in 'Mustn't Grumble' (Keith, 1994), an anthology of writing by women with disabilities, irony and mimicry can be used effectively in strategies of satirical challenge.

As a rhetorical strategy, irony is familiar in the works of the women in this study. However, irony is a strategy that requires a certain level of understanding of and appreciation of what is being said. As an example, I am sure 'this city's disabled woman' would agree with me on this point. However, this is only a joke if we understand the media's relationship with 'this city's disabled woman'. The stories of the participants in this study contribute to non-disabled people's appreciation of irony, wit and humour women with disabilities use to make sense of the world. Moi (1985) suggests that although we assume that authority and responsibility are incompatible with amusement this is often not the case. In Moi's opinion, exploiting stereotypes, and using sardonic humour, wit and irony have been and continue to be, powerful methods of resisting the hegemony of phallogentrism.

Kondo's analysis involves the use of irony as a means of resistance; in doing this Kondo's work is not unlike that of the French feminists such as Irigaray (1977) and Moi (1985) who posit strategies such as irony and mimesis. Destabilising the split between 'the public' and 'the private' by bringing resistant discourses into wider public circulation is a strategy that has been used to feminist ends. In her analysis of working life in a Japanese factory Kondo (1990) provides us with an example of the subversive possibilities inherent in these practices. Kondo notes the ironic use of the credo of 'company as family' as a means of expressing dissatisfaction. Kondo suggests that the literature on resistance is useful as it provides a forum for analysis of small acts of resistance to hegemonic ideologies, thus opening up exciting new areas of inquiry and leading us to consider unlikely places to look for resistance and protest. Introducing the notion of play, subtleties, ironic twists and creativity, Kondo develops the notion of resistance to include the notion of a ludic space, open to creative possibilities for subversion. The idea of ludic space is suggestive of toying with ideas; of tossing thoughts and feelings back and forth; of momentary kaleidoscopic distortions producing glimpses of possibilities for resistance.

Foucault, Irigaray, Moi, and Kondo share an interest in how we come to know ourselves and offer creative means by which these conceptualisations of self can be resisted or turned back upon themselves. These authors were chosen for their

attention to everyday practices and resistance at the micro level. A concern to challenge practices of marginalisation by exploring the assumptions upon which such practices rest flows through all these analyses.

The privileging of multiplicity and diversity these conceptualisations of the self suggest is not accepted uncritically. Haraway's (1988) notion of selves laid out on the table with self-induced multiple personality disorders captures the key point of these debates: the fear that normalcy and agency will be abandoned if we allow multiplicity, openness and the play of power in the 'crafting of selves'. Although this movement towards de-essentialising the self has engendered powerful debates, the potential it holds lead us to a place where the notion of fractured and multiple selves can provide the basis for a politics. The concept of fractured and multiple selves challenges the production of non-disabledness as the norm and disability as Other by exposing the instability and fragility of identity categories. Nevertheless this privileging of *selves* is contingent upon a space for moments of coming together, a place for shared goals, a unity beyond identity, in short the possibility that a usable remnant of community can be found.

Community

Community has always been a central construct in feminist politics. Apart from the phrase, 'a woman needs a man like a fish needs a bicycle', 'the personal is political' is probably one of the best known catch phrases of the second wave of feminism. The radicalness of this statement stands in its challenge to the idea that what happens in the private sphere (the home) is less important than what is achieved in the public sphere. In the 1990's the focus of this challenge has moved to a questioning of the notion that the personal and the social can be so easily divided. The critique of the fracturing of the personal and the social has arisen in the context of postmodern feminism's questioning of the ways in which selves are constructed (Trinh, 1989, Kondo, 1990, Probyn, 1993) and a renewed interest in the function and necessity of community (Trinh, 1989, Probyn, 1993¹⁸, Haber, 1994). Because of the location of this study, at an intersection between disability politics and feminism, this renewed interest in the idea of community, based on constructs other than simple deployments of identity, is extremely important.

¹⁸ See especially Chapter 6, 'Without *her* I'm nothing': Feminisms with Attitude.

However, the question of how the self, a founding construct of hegemonic, Western, colonial, Libertarian discourse could be of use in postmodern feminist politics of community remains. Possible answers to this question are discussed below. Feminism's traditional resistance to the phallogentrism of the legacy of the individuated self, combined with the feminist insistence on the primacy of community (or sisterhood), are perhaps the reason why feminist writing on the self insists on the self as a constituent of community. Kondo (1990) considers that even talking of 'a concept of self' links up with static, essentialised global traits, where selves can be discussed as a category quite distinct from power relations. However, we retain narrative conventions such as the self/world split because we need heuristically useful categories in order to achieve our goals (Kondo, 1990). Kondo moves from the notion of the essential self to an insistence on selves as multiple and communal - the possibility of a community of multiple selves.¹⁹ In a similar fashion, Haber (1994:1) (whose work radically challenges postmodernist thought while firmly remaining part of the postmodern body of knowledge) argues that the subject is always a 'subject-in-community':

..Since subjects are inscribed in language they are always cultural, historical, and social entities. This notion of the subject gives a place of privilege to community, for our interests are always the interests of some community or another.

Haber draws attention to a common feature in feminist postmodern analyses - the deconstruction of the binary logic determining linguistic codes. The split between self and community is disputed on the basis of a deconstruction of the binary logic of signification. The self, or selves, thus conceptualised are no longer in opposition to community they/we/'I' or 'i' become constituents of community.²⁰

On a practical everyday level, however, we come back to the need for a basis for solidarity that pays attention to the plural and protean nature of selves,

¹⁹ The privileging of community or collectivity stands in opposition to the analyses of postmodern theorists such as Baudrillard who question the existence of 'the social' suggesting that the social has collapsed or imploded (Chow, 1992). Foucault's notion of the social as a product of power/knowledge relations has been of more use to feminism. However, postmodern feminists take this analysis in new directions opening up further possibilities.

²⁰ 'i' signifies the personal subject, gendered, classed, of a specific ethnicity. 'I' signifies the all knowing authorial subject. See Trinh (1989:9).

community and culture. The idea of the interdependency of the terms 'private' and 'public' has political implications at the level of communal political action or as Haber would put it, at the level of the 'subject-in-community'. Haber's (1994) conceptualisation of the subject-in-community allows a recognition of the points at which our deviant behaviours intersect. Instead of seeing behaviours as idiosyncratic aberrations, a deconstruction of the ways in which deviance is constructed is possible. For example, a deconstruction of the historical pathologisation of disability and homosexuality might uncover possible intersections. The recognition of points of intersection provides a platform for the politicisation of marginalised voices (Haber, 1994). Uncovering the historical underpinnings of oppressions might encourage understanding of and empathy for people whose experiences are different from our own. Subjectivities may be thought of as infinitesimally variable but this does not (as has been suggested in critiques of the postmodern perspective) preclude action.

Research by Gibson-Graham (1994, 1995) illustrates how the notions of the subject-in-community or an insistence on selves as multiple and communal might work on a political level. Speaking of successful action by miners' wives to oppose the introduction of seven day shift rosters, Gibson-Graham (1995) documents the ways in which multiple and differing subject positions, located within various narratives and discourses, interact within an individual subject and recombine to produce moments of affinity and political identification. Gibson-Graham's analysis is discussed below as an example of the politics that might be inspired by a conceptualisation of the subject-in-community. This research is important in this study as it demonstrates both the political salience of understanding the self as multiple and contingent, and the depoliticising nature of strategies that maintain divisions between non-disabledness and people with disabilities.

The miners' wives in Gibson-Graham's study opposed the introduction of the seven day roster on the basis of its disruption to established patterns of family life. The three prime movers in this action shared identities as part-time workers. In addition, two women were members of a cot death fund raising and educational movement. Challenging the conceptualisation of miners' wives as subordinate supporters of male wage labour, the women who participated in this study catalysed the campaign against the introduction of the seven day shifts. Gibson-Graham suggest that under the dominant frameworks within which the lives of these women are theorised (that is, the client/victim/ pathologised individual representation of liberal discourse or the proletariat/militant/supporter

cum leader representation of socialist discourse) tell only part of the story. Their militancy when viewed under these frameworks is indeed viewed as an idiosyncratic aberration. Utilising a feminist postmodernist framework in which 'multiple selves' combine at a point of political action, Gibson-Graham's narrative tells an alternative story, in which selves and communities are constituted through combinations of 'private' and 'public' narratives and discourses that produce particular political subjectivities.

Theorising the self moves us beyond the difference/identity debates to a place where difference is taken into account but not at the expense of community. In Probyn's (1993:168) words, we must '...pay attention to how our various selves are folded and pleated together...'. This point is illustrated by Micheline's account of her feeling of enlightenment upon the realisation that; although the problems might be different, non-disabled women also have uneasy relationships with their bodies (in Campling, 1981). Probyn sees the self as offering the potential to facilitate an opening of perspectives rather than as signifying a return to the individual. Far from being a recentring of myself in relation to herself, this questions the very grounds that separate us (Probyn, 1993). Taking the idea that Foucault (1988a) presents in 'The Care of the Self', that the self and political activities are linked, Probyn (1993:169) suggests that 'as an activity of theory and of being, the self is not an esoteric question; it is not to be held at a distance'. In Probyn's analysis the self is not an abstract theoretical concept. Probyn writes:

The care of the self thus can only be conceived of and performed within the exigency of caring for others and for and within our distinct communities. The self is not an end in itself, it is an opening of a perspective, one which allows us to conceive of transforming ourselves with the aid of others. Far from being a self-centred or self-centring action, this is to radically de-centre our selves, to work at the extremity where my self can be made to touch hers. Stretched to the breaking point where individuality ceases, the self designates that point of possible contact when it is neither a question of 'who am I?', nor a separate one of 'who is she?' Pushed to the end of their distinct logics, these questions re-find themselves together at another point, at the point where we are both at the limits of our selves. Here the view is different, and from this perspective we again put ourselves to 'the

test of contemporary reality'. As Foucault (1989:36²¹) puts it, this test is then to discern 'the chinks where change is possible and desirable, as well as to determine the precise form that this change should take'.

The idea of the limits, of working at the limits of ourselves, facilitates the destabilisation of binary questions such as 'who am I?'/ 'who is she?'. In this study - designed to facilitate dialogues between feminism and women with disabilities - strategies designed to destabilise the boundaries between I and she, are politically salient. Working at a place where we are both at *the limits of our selves* we might *re-find* ourselves together at *another point* between the experiences of disability and non-disabledness. Probyn's assertion that the self is not an esoteric question and her critique of the grounds that separate selves are important constructs, within the context of the present study. Strategically privileging an identity other than my own means that the question of 'who am I?' 'who is she?', can more productively be conceptualised as, 'who am I... for her?'.

Probyn's analysis problematises the binaries between the norm and the Other by questioning the boundaries between selves. Conceiving of the self as multiple and contingent, and thus destabilising the boundaries between the non-disabled norm and disability as Other, is one of the aims of this study. Foucault's (1982:216) analysis can be used to approach the question of the de-centred and multiple self in another manner. Suggesting that 'who am I' is 'unique but universal and unhistorical', Foucault instead poses Kant's question: 'what are we?'. Foucault suggests that in the sense that Kant used it to ask 'what is going on just now... what are we? in a very precise moment of history' this question '...appears as an analysis of both us and our present' (Foucault, 1982:216). This particular postmodern feminist study is implicated in the production of *what is going on right now*. From this perspective the imperative question is not 'who am I... for her?' but, 'what am I... for her?' (right now in the context of this project).

Asking, 'what am I... for her?' and, making connections between myself (as a non-disabled feminist researcher) and herself (participating in this study as a woman with a disability), I focus, in the following section, on the potentialities of the Foucauldian idea of working at the limits. This work at the limits of

²¹ Poster, Mark (1989) Foucault, le present et l'histoire, in Michel Foucault, Philosophe. Paris. Seuil, cited in Probyn (1993:169).

myself and herself is designed to create dialogues between feminism and women with disabilities.

The Limits

In this section it is argued that working at the limits of what we know, or what we understand as ourselves, searching for ways to see beyond these limits and to come to understandings of the embodied realities of Others, has powerful emancipatory potential. The notion of limits is integral in Foucault's later work on the self. Foucault advocates a movement away from totalitarian theories and meta-narratives, towards a 'limit attitude'. With his notion of a limit attitude Foucault encourages the practice of scrutinising the everyday practices and ideas that we commonly accept as natural. He suggests that:

A certain fragility has been discovered in the very bedrock of our existence - even, and perhaps above all, in those aspects of it that are most familiar, most solid and most intimately related to our bodies and to our everyday behaviour (Foucault, 1980:80).

Foucault's purpose was to show people that they are freer than they feel. He achieves this by calling into question things that we accept as true, familiar, and natural. Foucault (1980:81) relates this instability, or fragility in the bedrock of our existence, to a movement towards local criticism and the '*insurrection*²² of *subjugated knowledges*' (emphasis in original). I believe that this notion of the insurrection and legitimation of previously silenced knowledges and discourses, can be appropriated in the service of creating dialogues between feminism and disability, of thinking through new ways of achieving political outcomes and of subverting practices that Other women and disability.

This idea of the possibility of thinking differently, of pushing at the logic of the limits, at the gaps between 'who am I?' and 'who is she?', is one of the major attractions of Foucault's work for me. O'Farrell's (1989) analysis of this limit attitude, demonstrates the importance of this concept in a study that seeks to destabilise practices that Other people with disabilities.

²² The insurrection of subjugated knowledges refers to the rising of knowledges in opposition to established authority. In terms of Foucauldian theory this idea can be linked to the notion of resistance.

...If instead of looking at totalities, the 'edge' (limit) which separates the Same and the Other²³ could be analysed and described, perhaps an insight into the reality or truth of the Same and the Other could be gained. ...A thought of the Limit makes it possible to resist the dreary pressure of the Same and to actively seek out the limits and go beyond them (1989:32).

Taking the idea of work at the limits and questioning the ways in which sexism is tied to disableist cultural practice is one way in which this idea of thinking differently might be achieved. It could be said that a critical thinking through the Same (myself, that which is known, feminist discourse) and the Other (difference, that which is silenced - unknown, women with disabilities) is central in this dissertation. Yet 'feminism' and 'woman' are Other at the same time as they are Same. I have found myself positioned as Other, outside of disability. Often in the space of a sentence I have been woman and therefore Same and non-disabled and therefore Other. Trinh (1989:90) describes this process eloquently:

If i can be I or i, you and me both involved. We (with capital W) sometimes include(s) sometimes exclude(s) me. You and I are close, we intertwine; you may stand on the other side of the hill once in a while, but you may also be me, while remaining what you are and what i am not.

The clash and inclusion or melding of Same and Other offers a chance to push at the limits; a movement toward decolonising our own imaginations; another way of thinking through the self; a recrafting or recasting of selves; a pathway of resistance; and way of boundary crossing.

The positions fluid and shifting selves occupy and the mobile positionings of Otherness affect the constitution of communities. Feminism and woman may hold the subject position Other. An historical analysis of feminism in the context of the lives of women with disabilities exposes feminism as hegemonic and

²³ 'The Same' tends to refer to known or hegemonic subject positions or discourses, while connotations of the unknown or something which is outside of mainstream thought and is silenced or marginalised are associated with the 'Other'. The association of women and the 'Other' is an established concept in feminist thought. In 'The Second Sex' Simone de Beauvoir (1988) asserts that from the beginning man has named himself self and women Other.

disability as Other, while an analysis of women and feminism within the context of disability politics exposes women and feminism as Other. These practices of inclusion and exclusion change constantly. Thinking these practices differently might be productive of fruitful dialogues. However, at a moment in disability politics when identity is an important founding construct, the problem of positing a politics of inclusion that does not involve a radical destabilisation of essentialist notions of belonging remains.

Is the risk of looking to the intersections of Same and Other, of working at the limits, strategically useful for disability politics in this particular postmodern moment? In this study it is argued that the risk of looking to the intersections of the Same and the Other is strategically useful and that this can be achieved through encouraging dialogues between feminism and women with disabilities.

The idea of working at the limits provides some useful starting points for an exploration of these ideas. The notion of movement across boundaries or transgression is integral in Foucault's work on the limit. Transgression suggests the possibility of treading on toes, of offending notions of political correctness, of overstepping moral boundaries, and as such is an area that needs to be approached with caution. In Foucauldian analysis transgression indicates where limits lie (O'Farrell, 1989). Transgression of limits can only occur where there are limits to cross and we cannot know of the existence of a limit which is not transgressed (O'Farrell, 1989). If we cannot know of the existence of a limit that is not crossed then again we come back to the notion of risk.

So where do the risks and possibilities for these limits, these gaps and ruptures in the discursive field of our imagination, lie? In the risk of political incorrectness, when I chose to analyse disability, as a non-disabled person? In the positioning and repositioning of Same and Other, the intertwining of I and i? And perhaps in the writing of this thesis, where 'I/i' find myself speaking for women with disabilities - 'i' am 'I' even as I/i seek to problematise this practice. In speaking for Others, I/i reinscribe Otherness.

Anti-racist authors provide us with some clear examples of the problems associated with authoring and the processes of Othering. For example hooks (1990) cautions against speaking about, or for, the Other as a mask for oppressive practices. Writing through my self in this particular postmodern

moment I am aware that I transgress boundaries of political correctness²⁴. At the same time I believe that this transgression is strategically necessary and productive, a means by which it might be possible to glimpse where the limits lie. By self consciously writing myself into the process as *Author I/i* destabilise the discourses that establish me as an *Authority*. Asking the right questions, not ‘what (or who) am I?’, or ‘what (who or) is she?’, but ‘what am I...for her?’, is imperative. But, ‘what I am...for her?’, is a question I cannot answer. I can claim, however, this bringing together of women with disabilities and feminism as part of the attempt to produce knowledges that write me in the margins rather than the centre of the text.

Another example of how the notion of working at the limits of the Same and the Other might produce new discourses can be found in postmodern anthropological work, especially work where the practice of Othering is called into question. This body of knowledge provokes consideration of the ways in which sexism, and other cultural practices that privilege the colonial male norm are historically tied into racist practice and the process of authoring. New resistant discourses existing on the margins of mainstream anti-racist critiques have emerged. These resistant discourses, such as the work by women of colour (hooks, 1990), work on institutional racism (Spoonley, 1990), and the new racism (Gilroy, 1987, Nederveen and Parekh, 1995), attack cultural displays of racism in different ways and often from different ideological perspectives. Each of these discourses offers a partial vision founded on particular anti-racist standpoints. Work by women of colour privileges women’s knowledges, work on institutional racism focuses on structural factors and postmodern anthropology questions the ontological and epistemological bases of knowledge production (such as the place of the author in the production of the text). These resistant discourses work at specific points in the anti-racist critique.

Dialogue between feminism and the anti-racist critique have produced a body of knowledge more relevant to the lives of women of colour than its apparently gender neutral predecessors. Perhaps then, work at the limits of feminism and disability can produce knowledges more relevant to the lives of women with disabilities. For example, this study suggests that privacy is an important issue for women with disabilities. A feminist exploration of the concept and meaning

²⁴ I am taking the risk that this study appropriates the voices of Others. Am I taking their stories and using them for my own ends? (See hooks, 1990 in Chapter Three of this thesis).

of privacy, which takes experiences of disability into account, might produce more subtle understandings of privacy issues.

Feminism is not necessarily the most appropriate or strategically expedient discourse for disability politics or women with disabilities to engage with. Feminism may be merely another technology of power operating upon the lives of women with disabilities. Asking women with disabilities to speak the truth of themselves may simply reinscribe the binary between 'the knower' (for example, a non-disabled researcher) and 'the known' (women with disabilities as the research subjects). Thus, feminist research on women with disabilities would reinforce relations of power and powerlessness. In addition the information shared by the women in such studies could be used to further regulate their lives. For example, information on the tasks carried out by carers could be used to further regulate the tasks that are considered permissible under current Social Welfare provisions.

Bhavnani (1993) suggests the need to look at why and how knowledge is produced, who produces it and how it becomes privileged. If we accept that scientific insights are social in origin, then the sexist and racist assumptions underpinning research on the brain size of black people and white women, undertaken around the turn of the century, to explain apparent differences in cognitive abilities between these groups and white men can be problematised (Bhavnani, 1993). Similarly we can problematise Truby King's hystericisation of the female body. King who founded Plunket (an organisation dedicated to population growth and child welfare) in New Zealand, believed that learning and studying caused wandering ovaries and thus interfered with women's natural fertility. King's hypothesis coincided with a political interest in the expansion of the white-colonial population.

A historical analysis of the uses and function of King's hypothesis can be utilised to problematise the naturalisation of the link between disability and deviance. Discourses such as those supported by King above have been refuted and now seem ridiculous. These examples illustrate Foucault's idea that '...the self cannot be seen as a stable ontological entity; rather the self is a line of analysis that articulates the epistemological and the ontological' (Probyn, 1993:128). Asking 'what am I... for her?' articulates a line between myself and herself at the same time as it proposes that these selves should be interconnected.

Probyn (1993:128) continues her analysis of selves through an analysis of 'Deleuze's reading of Foucault and his metaphor of "le pli" (the "pleat", the "fold" the "doubling up")' as a further insistence '...upon the pliable nature of the self as form and not substance'. The interconnectedness of selves is a feature of the postmodern call to politics based upon an ethos of permanent critique. The following quote gives us some idea of Foucault's attitude towards political programmes:

The critical ontology of ourselves has to be considered not, certainly, as a theory, a doctrine, or even as a permanent body of knowledge that is accumulating; it has to be conceived as an attitude, an ethos, a philosophical life in which the critique of what we are is at one and the same time the historical analysis of the limits that are imposed upon us and an experiment with the possibility of going beyond them (Foucault, 1984:50).

This study argues against the relegation of disability to the negative and negated end of the disabled/non-disabled binary, through a critical engagement with the question of 'what am I... for her?'. Identifying these limits requires constant attention to the challenges issued to non-disabled people within disability politics, such as challenges to the representation of disabled people as 'dustbins of disavowal' (Shakespeare, 1994). This dialogue held at the limits of disability politics and feminist politics is intended to engender new possibilities.

Conclusions

In this thesis it is argued that in order to be effective, an emancipatory politics must seek to go beyond the limits of what has gone before. The reading of the work of Foucault suggested in this analysis, and the selection of postmodern feminisms presented here, reflect a concern to suggest politically engaged strategies. Foucault's ideas are used to achieve particular purposes. This in itself is a Foucauldian idea. Foucault was concerned that ideas should be borrowed from his analyses. Foucault was interested in the ways in which theory could be used as a political tool:

All my books, ... are, if you like, little tool-boxes. If people want to open them, use a sentence, an idea, an analysis as a screwdriver or a spanner in order to short-circuit, disqualify and break systems of

power, including if need be, those which have given rise to my own books, well, so much the better! (Foucault, 1975²⁵, in O'Farrell, 1989:110).

Probyn (1993) analyses Foucault's idea of using the self as a tool box in the production of strategic knowledges:

Conceived of as a 'tool kit', the self both expresses the specificities of local power relations and allows us to figure them in ways that can be analysed. In that the self is seen as both practice and the problematisation of practices, the investigation of power struggles and relations is undertaken through the self, thus ensuring that the analysis is both historical and reflective of the given situation. It is a self conceived of as within the force of a critical attitude (Probyn 1993:128).

Foucault's work and that of feminist theorists has been used as tool kits to think through the self, communities, and the limits. Thinking through these topics and the related issues of the death of the subject, agency and structure and the question of 'what am I... for her?' opens up spaces for feminism and people with disabilities to make claims on the basis of differences. A postmodern reading of these discourses privileges a lack of absolute universal concepts of truth and justice; here nothing is regarded as natural or outside of power relations.

In this chapter the question of 'what am I... for her?' has been approached through a critical engagement with postmodern understandings of the self. This critical engagement considers ideas about relations of power and powerlessness, authorship and authority, new ways of thinking through human agency and a critique of dualistic understandings of self and Others. Legitimizing strategies such as the authority of the researcher and the masculinity and ablebodiedness of the master subject are called into question. Ideas about human agency and the ways in which these ideas impact upon choices of potential theory are also discussed.

This analysis of questions around authority and human agency presented in this chapter is designed to open up spaces for local struggles. Thinking through the

²⁵ Des Supplices aux Cellules, (Interview with Roger-Pol Droit). Le Monde, (21, February, 1975), p.16.

self or selves in this way allows the voices of those silenced by the authority of the master subject to be heard. Links between feminist postmodernism and disability politics have been made in an attempt to push at the limits of current political interventions by creating dialogues between the two bodies of knowledge.

Within the context of the postmodern movement away from meta-narratives, the master subject and the authorial 'I', Foucault (1977:208) suggests that:

...theory does not express, translate, or serve to apply practice: it is practice. But it is local and regional... and not totalling. This is a struggle against power, a struggle aimed at revealing and undermining power where it is most invisible and insidious.

This study aims to contribute towards the production of local theories and knowledges and to undermine the workings of power in the places where it is most difficult to detect. Using this knowledge to destabilise the ways in which disability is constructed, and has been constructed historically, might enable us (feminists and women with disabilities) to learn to think differently, to think with a 'limit attitude'. In the following chapter (Chapter Three) the production of new theories and the practices of thinking differently are approached through the question of 'what am I... for her?'. Research practices that Other the subjects of the research are called into question and a participative framework is developed.

Section Two:

Theories and Stories: Minding the Method

The information presented in Chapters Three and Four can be understood as a representation of my journey through the research process. Throughout this process the methodological parameters of the study shifted and changed in response to my understandings of the research project and the inputs of the participants. My position as a non-disabled researcher, studying the lives of women with disabilities, impacted upon the research in multiple ways.

Chapter Three:
The Theory of the Method

Avoiding Appropriation of the Other

I am waiting for them to stop talking about the 'Other' to stop even describing how important it is to be able to speak about difference. It is not just important what we speak about, but how and why we speak. Often this speech about the 'Other' is also a mask, an oppressive talk, hiding gaps, absences, that space where our words would be if we were speaking, if there were silence, if we were there. This 'we' is that 'us' in the margins, that 'we' who inhabit marginal space that is not a site of domination but a site of resistance. Enter that space. Often this speech about the 'Other' annihilates, erases: 'No need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I write myself anew. I am still author, authority. I am still the coloniser, the speaking subject, and you are now at the centre of my talk'. Stop (hooks, 1990:151-152).

In a critique of the feminist impetus, from de Beauvoir (1988) to the present, to talk about and theorise the 'Other', hooks cautions against appropriation. Appropriation of the voice of the Other is an issue close to the heart of feminism and speaking for oneself rather than being spoken for is an important issue in disability politics. As a consequence *not* speaking for women with disabilities is a guiding principle in this study.

Other ethical issues such as power relations, reciprocity, empowerment, reflexivity and the processes by which 'Othering' occurs are integral components of this study. This study also documents a dialogue in which women with disabilities, the researcher, the women responsible for supervising this project and various written texts mix and collide. Tensions between theoretical consistency, political correctness, the method, and the participants, also contextualise the production of this text.

The production of disability as Other than the non-disabled norm is a central concern in this study. Identity, or the construction of differences between Others, therefore becomes an important issue. Appropriation of the Other does not make sense outside of the context of identity. If we have no concept of

identity then the notion of being *the same as* or *other than* other people has no purchase, as there is no Other to be Other to. Identity, identity politics and the issues discussed in Chapters One and Two, around identity/difference, and the self and the Other, resurface in this methodology. The issues raised above are approached through the critical lens of writings against appropriation of the Other.

Reflexivity in the research process is a component of this methodological movement against appropriation. My embodied difference from the research participants means that researcher reflexivity in this study is partially operationalised around issues of appropriation. Writing this methodology I find myself questioning my own position in the maintenance of the very structures I seek to destabilise. Am I taking the participants' stories and making them my own? Am I making myself author or authority at the cost of silencing the words of women with disabilities? Is the research empowering for the people taking part in the research? Am I talking for the Other? Has my speech become merely a more sophisticated method by which the voices of people already disadvantaged by society become more marginalised? These questions inform the theoretical framework utilised in this study. However, too much attention to questions such as these, for which there are no simple answers, merely shifts the focus away from other important issues. Lather (1991a:150) offers a path out of this potentially paralysing self reflexivity. She writes:

...While anything short of full collaboration cannot avoid some degree of objectification and speaking for others, we can aim towards an introspection/objectification balance.

Lather's (1991a:139) questioning of the ways in which emancipatory intentions '...might function as part of the technology of surveillance and normalization' leads her to propose this solution. Researchers do need to look at the place we as individuals, along with professions in general, play in the maintenance of oppressive systems (hooks,1990, Ballard, 1991, Lather, 1991a). The proposition that emancipatory intentions may not always be as liberating as they are intended to be informs this study. As argued in Chapter Two, the transparency of good intentions guarantees nothing Yeatman's (1994). In response to these cautions, this study has its basis in two related practices: First, a critical evaluation of the methods, methodologies, and epistemologies, informing research methods. Second, in taking the research in the direction of the viewpoints and critiques of the people who are the subjects of the research.

The remainder of this chapter documents my critical engagement with a range of literature related to participatory research methodologies. My search for an appropriate methodology was guided by a desire to make the research fluid enough to encourage the sharing of diverse and oppositional ideas and experiences, and at the same time structured enough to be useful in a concrete political way. The following selection of theoretical material was chosen on the basis of its relevance to and usefulness for this project.

Methodological Parameters

This methodology is informed by feminist theory, disability theory and postmodern theory. The authors discussed in this chapter are concerned to change the way we do research. They argue that change must take place on a variety of levels (from the theoretical to the practical) and in a variety of ways (including research practices, interview techniques, writing practices and the strategies used to legitimate the research). However, all the authors cited in this chapter are concerned to reframe the ways we gather and produce knowledge.

Introducing the Theoretical Perspectives

When I began this study, I imagined I would not find a great deal of literature relating specifically to participatory research methods, however, I was surprised at the rich history of feminist participatory models. The idea of participatory research methods in feminist theory is not new. Vaughter (1976), Wallston (1981), Du Bois (1983), Smith (1987) and Lykes (1989) conceptualised participatory models. Participatory models are particularly valuable to this project; by promoting the ethos of sharing power in the research process they mediate the line between identity politics and political pragmatism. At a time when identity is a politically expedient and popular tool within disability politics, participatory methods are important as they can be used in a manner that is sensitive to the play of identity. I argue that a participatory model allows a space in which diverse political issues can be simultaneously tackled. Participatory methods are designed to mediate against appropriation of the voices of Others and as such are commensurate with the aims of disability politics.

In keeping with an ethics of working with the principles of disability politics this study seeks to take into account the material realities of having a disability. A number of specific ethical and methodological questions (discussed in the next chapter) have arisen as a result of this. As well as offering insights into the experience of disability generally, disability theorists are interested in reconceptualising research methods, they offer a practical critique of main stream methods providing visions of the means by which the process of participation might be achieved (Ramcharan & Grant, Undated, Morris, 1991, 1991-1992, Felske, 1992, Oliver, 1992 Wicks, Terrell 1993, Ramcharan & Grant, Undated, Stehlick, 1994).

It has been argued that participatory models sit outside the auspices of mainstream science. As a consequence validating the research in ways that make it acceptable to wide ranging audiences is critical in achieving the aims of the study. Bhavnani (1993) suggests that epistemological concerns are often at the forefront of the projects of feminist research. Feminist empiricism, feminist standpoint theory, and postmodern feminisms explicitly foreground epistemological concerns. Issues typically addressed include: who are the knowers, who does the knowing, and the politics of who or what is known. Although each of these analyses contribute to this study, its epistemological roots are firmly grounded in postmodern feminism.

This methodology operationalises postmodern principles of paying attention to multiplicity and diversity in order to uncover previously subjugated knowledges. The work of the postmodern theorists utilised in this study, particularly those interested in emancipatory research methods such as hooks (1990, 1991), Foucault (1984), Lather (1991a) and Opie (1992, 1992a) mesh the methodological webs emerging in this chapter. This results in a specifically feminist postmodern methodological framework conceptualised through a critical engagement with Lather's (1991a) strategies for contributing towards the establishment of emancipatory ways of doing research.

Feminist Participatory Research

The participatory research theorists cited below offer a variety of methodological strategies. Arguing for a new paradigm in psychological research, Wallston (1981) suggests that there is a need to move beyond traditional methods. She argues that the narrowness of our methods shapes the

way we ask questions and the knowledges we produce. Vaughter (1976) constructs a 'participatory model' in which the research participants and the public become involved in all phases of the research. While Smith (1987) advocates a method which preserves throughout, the standpoint of the women involved. Du Bois (1983:108) focuses on epistemology, or how we come to know, suggesting that a critical analysis of the ways of doing scientific research is 'as important a focus for our scrutiny and creativity as is the actual substance of our enquiry'. I would argue that from a political perspective this critique at the level of epistemology is extremely important.

What is regarded as legitimate knowledge is constrained by the epistemological frameworks we utilise:

Recognition of the dynamics of power and control implicit in our research tools and of the differing forms of power and control the participants bring to the research situation, suggest the importance that the research process itself plays in constructing the data that is being gathered (Lykes, 1989).

Problematising the legitimation of knowledge and the basis of knowledge claims, plays an important part in projects that challenge the limits of what we know. Such projects allow us to look at previous knowledge claims from new perspectives.

The epistemological underpinnings of this study are discussed in the section on the feminism and science debates below. The particular epistemological framework utilised in this study has encouraged the revelation of particular knowledges and the suppression of others. However, choosing to use a method which is both feminist and participatory plays its own part in moving the research in particular directions. By their very nature, participatory models of research foreground issues of power in their rejection of the rigid separation between researcher and the researched. Documenting and analysing the underlying power relations in the research process is one way in which understandings of collaborative research are developed (Lykes, 1989). Feminist participatory research can be categorised as a method that challenges inequalities (Cancian, 1992).

Disability Theory

Disability theorists have developed critiques of the ways in which the experience of disability is known in society. A variety of alternative positions are articulated. Two paradigms have evolved within disability research. One views disability as a deficit, the 'personal tragedy model' - and one views disability as a societal problem (De Jong, 1984, Oliver, 1990, Sullivan, 1996). The debates in the disability literature are not limited to these oppositional paradigms. For feminist theorists these debates obscure the fact that researchers in both paradigms have ignored the role of gender differences in disability. Feminist disability theorists argue that the social reality for women with disabilities is a marginalisation due to their impairment and denial of their roles as women (Munford, 1990, Dossa, 1990, Felske, 1992). This lack of gender analysis in disability research leads Felske (1992) to argue the need for a new 'social action based' paradigm, which she labels 'women with disabilities - ways of knowing'.

This new paradigm, 'ways of knowing', relies on the assumptions that 'research from the margins involves two interrelated processes which connect the personal and political' (Kirby and McKenna, 1989:28). The first of these processes or assumptions is *intersubjectivity*: an authentic dialogue between all participants in the research process in which all are respected as equally knowing subjects. The second is *critical reflection*, an examination of peoples' social reality (Kirby and McKenna, 1989:28, Felske, 1992:7). Felske envisions a social action based research paradigm in which questions begin from the life experiences of women with disabilities.

That research tends to reflect what is important to the researcher rather than the priorities of those being studied is hardly surprising if little is known of the realities of the lives of a group of people being studied. The need to take into account the ways in which our subjectivities impact upon the research is addressed by Morris (1991, 1991-1992). Morris calls into question the 'us' and 'them' divide underpinning feminist research on caring. In her critique of feminist research on 'community care', Morris (1991, 1991-92) provides a good example of the ways in which our own experience limits our vision. She argues that the failure of feminist researchers and academics to identify with the subjective experiences of those who receive care, means that feminist analyses in this area come entirely from the point of view of non-disabled women. As evidence she

cites the fact that in the feminist literature on caring, nobody has made any attempt to study the subjective experiences of those who are cared for. Although involving the research participants in all phases of the research is an attractive prospect, at present there are few research designs which encourage negotiation beyond the descriptive level (Lather, 1991a).

The challenges issued by hooks (1990) and Morris (1991, 1991-92) above: that if research is *about* them but not *from* their perspective, then they continue to be the objects rather than the subjects of the research, continue to be valid as long as this type of research continues to be practised. The need to problematise the ways in which our subjectivities impact upon the research project is a common theme in the literature utilised in this chapter. Vaughter (1976) Wallston (1981) Ralston (1988) Kirby and McKenna (1989) Munford, (1989, 1992) hooks (1990) Morris (1991, 1991-1992) Lather (1991a, 1993) Felske (1992) and Opie (1992, 1992a) all question aspects of the ways in which research and theory contribute to the maintenance of oppressions. The problem - at a time when 'woman' and 'disability' continue to signify devalued subject positions is; how do we conduct research that is sensitive to the needs of women with disabilities? I have chosen to do this by utilising a 'participatory research' method that involves the research participants in both the substantive and theoretical components of the research. Participant analysis of their own and other participants' stories and analyses, and of my theoretical analysis of the Life History research is a major aspect of this method. Utilising a methodology self consciously labelled emancipatory, feminist and alternative, demands rigorous attention to validity questions. The call to do research differently brings with it the need to legitimate the new knowledges such research produces.

Feminism and Science: Legitimizing Strategies

The problem of legitimating alternative claims to knowledge, is debated in the arena of feminism and science. Much of the debate is organised around the emancipatory potential of doing science differently. Feminist critiques of science are often divided into three categories. These categories include: feminist empiricism, (Gilligan, 1982, Bem, 1987, Harding 1989) standpoint feminism (Hartsock, 1983, Keller, 1985, Smith 1987, Harding, 1989, 1990) and postmodern feminism (Haraway, 1988, 1990, Harding, 1990). Although the

epistemological bases of the arguments vary, these feminists all challenge traditional conceptualisations of what constitutes good science.

Feminist empiricism critiques the androcentric bias evident in scientific research on the basis that it is the result of insufficient scientific rigour. To put it another way, researcher biases could be eliminated if scientific principles of value neutrality and objectivity were strictly adhered to. Strategies such as recruiting more women scientists and promoting women scientists to positions of power are proposed. Feminist empiricism does not claim women as the ideal knowers. However, they do support the claim that the women's movement removes the blinders from our eyes thus enabling us, through closer adherence to scientific method, to see what has always been there more clearly (Harding, 1989). Feminist empiricists would suggest that, clearing away some of the androcentric debris of main stream science allows a better view of the real and knowable world.

On one hand feminist empiricism challenges some major assumptions in mainstream science. However, it can be argued that the emancipatory potential of such critiques is limited. Objections to the misuses of science and research can be dismissed as isolated incidents on the basis that they result from the improper application of scientific principles. The symptoms rather than the causes of scientific inadequacy are the focus of such critiques. Thus, the structural causes of inequality are obscured. On the other hand feminist empiricism is useful in that it provides a critique of science from within its own framework of justification. Feminism can be added in without a radical shift of scientific paradigms. Feminist empiricism supports participative strategies designed to enhance objectivity. Submitting the research to the research subjects for the purpose of eliminating interpretative bias or researcher effects, might be one such strategy. Such strategies are justified on the basis that they advance the principles of empiricism.

An alternative legitimating strategy is provided by feminist standpoint theorists. Standpoint theorists challenge that women have a privileged and less biased view of the world than their male counterparts. From this perspective scientific method is so thoroughly saturated in androcentric principles that those who make the knowledge claims (typically men) cannot see the biases they bring to their work. Like the feminist empiricists, feminist standpoint theorists argue that the viewpoint of the more oppressed members of society (women) is less partial than the view of those at the top (men). Changing overarching social structures

rather than working at the level of science itself, is conceptualised as the best way to initiate change. In this view, the oppressed, who are generally the 'objects', occasionally the 'subjects', but rarely the conductors of the research, are the ideal knowers and, therefore, the ideal bestowers of validity. Participative strategies that encourage collaboration or promote structural changes are validated by standpoint theorists.

The strategies offered by postmodern feminists both challenge and rearticulate those of the feminist empiricists and standpoint theorists. The stable conceptualisations of feminine identity on which the arguments of the latter two groups rest are problematic for postmodern feminists. Concerns about authority and the constitution of subjectivity raised in debates over the death of the subject (discussed in the previous chapter) inform these criticisms. Haraway (1988:583), articulates a particularly pragmatic version of the postmodern position. She argues '...there is good reason to believe vision is better from below the brilliant space platforms of the powerful'. However, rather than the essentialised deployments of epistemology or identity politics informing the analyses of standpoint theorists and feminist epistemologists, Haraway (1988:586) argues for a postmodern privileging of the view of 'the split and contradictory self'. Positing the notion of a complex, contradictory structuring and structured body, Haraway (1988) offers a politically viable vision of embodied subjectivity. This vision of the split and contradictory self provides a practical basis from which to operationalise her vision of situated knowledges as the basis of scientific study.

Haraway's strategic splitting of the self complements Foucault's notion of work at the cusp of the Same and the Other (discussed in the previous chapter) that is at the limits that we may go beyond (Foucault, 1984). Transgression can only occur where there is a limit to cross and we can not know where the limits lie unless we transgress them (Foucault, 1984, O'Farrell, 1989). Therefore searching for the limits involves the notion of risk, or a dive into the unknown. For example, in this study, the risk exists that political aims will not be achieved and that the time and energy of the people involved with the study could have been more productively engaged in producing traditional, large scale, statistically credible research results.

The whole notion of participatory research methodologies, of privileging aspects of the research that remain substantively obscured in traditional conceptualisations of validity and objectivity, can be conceptualised as a push at the limits. Stating biases, glitches, and negotiations between researcher and

participant, encouraging participants to retell their stories in ways that they feel more comfortable with and acknowledging the places where the researcher's analysis draws from the analysis of the participants, challenge the limits of traditional conceptualisations of validity and objectivity. Relations of power between the researcher and the participants are acknowledged, problematised and written into, rather than out of, the method.

The postmodern feminist framework within which this study is situated concerns itself with the way in which power operates throughout the social network. This study is not informed by a doctrine that promises transcendence but by a postmodern ethics of partiality and local enquiry. Foucault (1984:47) suggests that '...the theoretical and practical experience that we have of our limits and of the possibility of moving beyond them is always limited and determined; thus we are always in a position of beginning again'. Alternative analyses of how knowledge is produced and the consequences of modes of knowledge production in terms of what it is possible to know are the critical mainstays of this study. If we could learn to see the world through different more interconnected lenses, then respect for ways of knowing that are different from our own might develop.

I argue that legitimating knowledge on criteria other than those we have been taught to acknowledge, is one way in which respect for presently subjugated knowledges might be operationalised. Developing ways of doing research that capture and popularise these marginalised knowledges is an essential part of this. A rigorous and on going critique of the epistemological underpinnings of knowledge claims is essential if these methodologies are to be acknowledged as credible sources of knowledge.

Key Factors in the Methodological Web: Postmodern Feminism, Objectivity, and Validity

Objectivity and validity are key constructs in establishing credibility in the social sciences. An insistence on the mobile and diverse and partial nature of the concept of 'truth', accompanies postmodernist critiques of the stable foundational principles informing previous knowledges. Postmodern feminists simultaneously critique and reframe notions of objectivity and validity. It can be argued that if feminist knowledges are to be taken seriously, epistemological bases for our knowledges must be rigorously established.

The epistemological bases of mainstream science's claims to objectivity are the starting point for feminist critiques of objectivity. Bhavnani (1993) suggests that the historical relationship between science and society has always been at the centre of feminist challenges against positivism. Postmodern feminists argue for the historically situated nature of claims to truth and objectivity. Haraway (1988) argues for a recognition that all knowledges are situated within particular contexts. Situated knowledges, the issue of who can know and how we come to know, are reoccurring themes in the literature on feminism and science (Grosz, 1988, Haraway, 1988, 1989, Harding, 1990, 1991).

Like objectivity, validity gets a radical reworking within postmodern feminisms. Postmodernism challenges the idea of the truth as fixed and stable suggesting that what can be known and what we acknowledge to be valid is produced through discourse. Likening the attention validity receives in the human sciences to Foucault's analysis of the modern preoccupation with sexuality, Lather (1993:674) presents validity as a fertile obsession, a 'limit question' of research; a question that can be 'neither avoided or resolved'. In order that knowledges such as those produced through this study are regarded as legitimate it is necessary to confront the issue of validity.

One means by which the problem of establishing validity has been addressed is via a strategy known as triangulation. This strategy, which involves using a combination of methodologies, to study the same phenomena, is gaining popularity. Hera (1995) suggests that triangulation can be used as a means of establishing validity outside of traditional positivist research frameworks. Triangulation can mean using several kinds of methods or data, including both quantitative and qualitative approaches (Patton, 1990). Validity needs to be established in relation to each aspect of the research and in relation to the triangulation of methods. Thus, validity becomes a multiple rather than unitary concept.

Another aspect of triangulation involves the comparison of research findings utilising a variety of analytic repertoires. Such a strategy establishes validity in a different manner. Comparative analyses of the same data using different analytic repertoires highlight the ways in which knowledge is produced. Analysing the same research material through a variety of different theoretical perspectives, Gibson-Graham (1995) draws attention to the potential different analytic repertoires have to change research outcomes. Strategies such as this draw

attention to the necessity of establishing and stating our biases and openly, and of explicitly stating the bases on which we validate our claims.

Triangulation is an excellent strategy for establishing the validity of research if the resources are available, but with this 'fertile obsession', this 'limit question' of research, there is again the question of risk. Is the production of quality research taking a back seat to the validation of the research findings? It could be argued that establishing the validity of the method is a 'limit' that stifles a movement beyond. To this end, I agree with Lather (1993), obsession with validity is fertile ground for enquiry. An exploration of the possibility of moving beyond current conceptualisations of validity could productively fill another chapter. However, in the present postmodern moment, the quality of quantitative research and the practices involved in legitimating and validating such research are intimately linked. Therefore, in the interests of fulfilling the political objectives of this project, it remains firmly situated within a framework concerned with questions of legitimation and of building validity into the research process.

The political objectives of this study also led me to search for a methodology that enabled me to address the question of the validity of my research method for the research participants. A method that enabled me to ask the question of, 'what I (the researcher) am for her (the research participant)?', in terms of the objective of destabilising the conceptualisation of disability as other than the norm, was needed. This question led me to the work of Lather (1991). Lather's research strategies are guided by political imperatives. She argues for an empirical research method openly committed to a more just social order. Lather points to the problems involved in having subjective research - in which the researcher discloses and works with their value base - recognised as legitimate scientific knowledge. She writes:

emancipatory knowledge increases awareness of the contradictions distorted or hidden by everyday understandings, and in doing so it directs attention to the possibilities for social transformation inherent in the present configuration of social processes (Lather, 1991a:52).

Lather's Five Steps

Lather's work is grounded in a concern for the practical workability of postmodern research methods. Reflexive practices that attend to the legitimacy and validity of theory and practice, drive Lather's analyses. In terms of this study, her work is particularly important for its provision of practical guidelines for establishing participatory methodologies. Adapting and building upon Lather's suggestions and incorporating the work of feminist, postmodern and disability theorists the conceptual framework informing this study with women with disabilities is outlined below.

In Chapter One it was suggested that 'the front line battles in the politics of disability begin from the experience of disability and utilise this experience to argue against practices of marginalisation'. Lather's work begins from the premise that the first step in critical inquiry is to ground the research in the experiences of the people being studied. The idea of beginning research from the experience of the research *subjects*, would be an unlikely cause for contention among the authors discussed in this chapter. However, the means by which this suggestion is operationalised and the various justification strategies used to defend this position would stimulate wide ranging and contentious debate. This seemingly simple principle cannot be easily dismissed.

A strategy for beginning research from the experience of the people being studied articulated by people with disabilities, argues for control of the resources used to conduct the research. Ramcharan and Grant (undated) argue that research currently being undertaken is not appropriate to people with disabilities. They advocate a system in which the researcher is funded by and accountable to 'individuals with a disadvantage'. I agree that this particular kind of collaborative research is an extremely effective means of ensuring that the world view of the research participants is included in the research design. However, I believe that control of the funding is insufficient in itself. To be an effective part of the emancipatory research project collaborative research needs to operationalise reflexivity and accountability at all stages of the research project, not merely in terms of who controls the funding.

An alternative position advocated by people with disabilities, positions people with disabilities as the 'ideal knowers', in all facets of the research process (Morris, 1991, 1991-92, Wicks & Terrell, 1993). This position is

comprehensively articulated in Morris's (1991, 1991-1992) well reasoned critique of feminist analyses of community care, outlined in the section on disability theorists above. However, rather than arguing for new ways of doing research, Morris's analysis simply replaces the us, feminists with an us, people with disabilities. This simple deployment of identity politics simply replaces one partial way of knowing the world - in this case feminism, with another equally partial, way of knowing the world - disability. The 'us' and 'them' dichotomy is reinscribed.

Positioning people with disabilities as the 'ideal knowers' ensures that research begins from the experience of disability. However, the positioning of disabled against non-disabled does not challenge the binary between non-disabledness as the norm, and disabledness as the marginalised Other to this norm. Pitting disabled against non-disabled identity denies the potentials inherent in basing arguments on factors other than identity. If arguments are made solely on the basis of identity then issues such as allocation of government funds (funding buses with disability access, for example) remain special issue cases rather than issues related to the wider public good. It can be argued for example, that accessible buses are of benefit to people in the community other than people with disabilities; older people, adults with young children and people with temporary injuries all benefit from the provision of more accessible buses. The reinscription of this dichotomy between disabled and non-disabled also excludes non-disabled people who can be utilised strategically to further the aims of people with disabilities.

The problems associated with positioning one identity against another are eruditely exposed in the literature often referred to as the work of women of colour. hooks (1990, 1991, 1992) is especially important in this project. Rather than retreating into identity, she delves into questions of identity placing them firmly in the spotlight. Racist assumptions, 'the logic of the same'¹, and notions of fixed identity are all disrupted by hook's strategies. Irwin's (1990) challenge to Maori feminists fulfils a similar function. Challenges to feminism are made by those who see feminism as pertaining only to Pakeha women and therefore as irrelevant to Maori. (Similar critiques of feminism are made by women with disabilities). Irwin (1992) counters this claim pointing out that the experiences of Maori women and men are not the same. Beginning the research from the

¹ A denial of difference; the assumption of a level playing field, in which everyone has an equivalent chance of winning.

perspective of the people being researched becomes a political 'hot potato', when multiple and contradictory subject positions are claimed by the proposed participants of a group.

In this thesis I argue that, a politics that takes into account the various aspects of our multiple selves and at the same time challenges existing relations of power, is required. Foucault's insistence on the centrality of power relations and thus related issues such as appropriation of the voice or text of the Other, kindles feminism's relationship with the work of this author. Foucault's analyses are intended to be emancipatory and as such, the notion of not wanting to speak for others is important in his work. Foucault refuses to speak for any particular group because he is 'wary of his ability to transcend his particular normalising discourse' (Haber, 1994:93).

*...The intellectual discovered that the masses no longer need him to gain knowledge: they **know** perfectly well, without illusion; they know far better than he and they are certainly capable of expressing themselves (Foucault, 1977:207) (emphasis in original).*

In this same text Deleuze speaks of the value of Foucault's work on the '...indignity of speaking for others' (1977:209). The tone of patient exasperation in Irwin's (1992) call for self determination for Maori supports Foucault's stance on this issue. 'We don't need anyone else developing the tools which help us to come to terms with who we are. We can and will do this work. Real power lies with those who design the tools - it always has' (Irwin, 1992:5). For Irwin a participatory research practice, beginning from the experience of being Maori, would involve a rewriting of every aspect of research practice. Pewhairangi & Pewhairangi (1996²) also suggest that connections to whanau are vital in the development of trust and sharing of information. Collaboration in the redesign of the research tools, beginning from the perspectives of the people being researched is clearly being called for.

This study is intended to contribute towards collaborative research becoming a legitimate means of knowledge production, and to enable myself and others to be involved in this kind of research in the future. How then is the issue of

² Pewhairangi, Irene, & Tu Pewhairangi (25, May, 1996). Meeting about Maori Oral History Research.

beginning the research from the perspective of the people being interviewed to be achieved in a politically practical manner within the present social context? Proactive practices such as attending to relations of power within all aspects of the research, including choices of method, are a vital part of this process.

Beginning the research from the experience of people being researched sets the scene for Lather's (1991a:63) second suggestion, that research should be a 'fundamentally dialogic and mutually-educative enterprise' towards cultural transformation. In other words, reflexivity should be practiced throughout the research process. Practices such as systematised self-reflexivity (Boyles, 1993) and a reflective approach which affirms interconnected ways of knowing the world (Fook, 1996) can be utilised to achieve this aim. This suggestion complements political strategies discussed elsewhere in this thesis, such as calls for non-disabled people to develop an understanding of the realities of having a disability; strategies that foster shared understandings and postmodern feminism's advocacy of dialogic methods in which women come together to work through their differences in order to achieve political outcomes (hooks, 1990, Sawicki, 1991).

People with disabilities are already operationalising Lather's first two suggestions of beginning from the experience of the people being represented and of using dialogic methods. 'People First' is an organisation in which these suggestions are firmly on the agenda. Self representation for people involved with 'People First' begins with dialogues between people with disabilities and non-disabled people. Beginning from the experience of people with disabilities, and ending in practices of self representation, that challenge both people with disabilities and non-disabled, 'People First' is an organisation in which the research practices suggested by Lather would fit well.

New strategies for representing dialogic methods are advocated by Strathern (1987) and Opie (1992a, 1994). Strathern (1987:289) writes of creating a relation with 'the Other'; searching 'for a medium of expression that will offer mutual interpretation, perhaps visualised as a common text, or a dialogue'. Opie (1992a:58) is concerned to move beyond the '...“subject-become-object” status of the participant in relation to the researcher...'. Opie suggests that '...the writer should consciously attempt to move away from a uniform textual surface, which represents only the researcher's voice, to the creation of a report which is more fissured, that is, one in which different and often competing voices within a society are recognised'. Strategies, such as those put forward by Strathern and

Opie, are aimed at reducing specific practices of appropriation in the research process. Although group interviews were not undertaken in this study, the principles of dialogic research outlined in this section inform the research and representational practices utilised in this study.

One of the ways in which such dialogic practices can be encouraged is through encouraging the research participants, including the researcher, to examine and problematise their current understandings of their position in society. This is Lather's third guideline. I agree with this idea in principle. However, I have difficulty with the subtleties of Lather's argument. Lather writes:

...Critical inquiry focuses on fundamental contradictions which help dispossessed people see how poorly their 'ideologically frozen understandings' (Comstock, 1982:384) serve their interests. This search for contradictions must proceed from progressive elements of participants' current understandings, what Willis (1977) refers to as 'partial penetrations', the ability of people to pierce through partial penetrations in incomplete ways that, nevertheless, provide entry points for the process of ideology critique (Lather 1991a:63).

I have two major criticisms of this idea. First, the opening sentence implies that because someone is marginalised by society they are necessarily experiencing a kind of false consciousness. Although part of my project is to share my knowledge of critical theory with the participants in the study, I feel that the first statement unproblematically privileges the researcher's understanding of the world. What kind of class and cultural assumptions inform claims that the view of the researcher is superior to, or 'truer' than, the view of the person being researched?

My second criticism is that although I believe contradiction can be a fertile site for emancipatory breakthrough, I do not believe it is necessary to work towards resolving contradictions in order to achieve emancipatory ends. Foucault's (1978) writing on the workings of power can be utilised to provide some insight into this. Foucault (1978:95) suggests that power is 'strictly relational', the existence of power depends on a multiplicity of points of resistance. If we consider that the contradictions in our lives are often sites of fascination and tend to provoke thought and debate, then contradictions are fertile ground for resistant discourses. Points of contradiction have the potential to expose relations of power, Foucault's 'mobile and transitory points of resistance' -

which produce cleavages in society ‘...that shift about, fracturing unities and effecting regroupings’ (Foucault, 1978:96). Thus contradictions have a productive place in our lives and are ongoing components of an emancipatory project. With these thoughts in mind, I would reconceptualise this guideline as encouraging research participants to problematise our current understandings of our various positions in society by exposing relations of power.

Practices such as follow-up interviews in which participants engage with the researcher’s analyses hold the greatest potential to promote examination and problematisation of current understandings of our various positions in society. The principle of gathering the responses of the research participants is key in this study. As Boyles (1993) suggests, people with disabilities should be fully included in the research process. An analysis of the contradictions in our lives is conceptualised as a site at which this can be achieved. Working with the contradictions we experience in everyday life can denaturalise the discourses and ideologies we experience as oppressive.

Lather’s fourth suggestion involves incorporating the considered reactions of those for whom the research is supposed to be emancipatory, into the method (Lather, 1991). She proposes the need to provide an environment that invites critical reactions to our accounts of their worlds (Lather, 1991). This suggestion is similar to disability theorists’ advocacy of ‘critical reflection’ and frameworks that promote inclusion (Kirby and McKenna, 1989:28, Felske, 1992:7).

Haraway’s (1988) theorising of power-sensitive conversations between actors positioned in unhomogenous gendered social spaces provides an epistemological basis for such strategies. Power-sensitive conversations are positioned as an alternative to the traditional researchers ‘god trick’, that is, coming from nowhere while appearing to come from everywhere. Haraway argues instead for situated knowledges. Decoding, transcoding, translation, and criticism; a science of the contestable and contested are necessary elements of Haraway’s sciences of situated knowledges. The principle of knowledges as situated, invites practices that nurture and value ‘critical reactions’.

Opie’s (1992, 1992a) strategies for avoiding textual appropriation are crucial means by which this outcome might be achieved. Opie (1992) is concerned that research is often interpreted by the powerful in such a way that the hegemonic world view of dominant parties in society is reinforced. Representing orality textually gives the research participants more clues to the interpretation of their

words and ways in which their words are likely to be utilised. Practices such as these are involved in creating an environment that invites the critical reactions of the research participants.

Existing studies can be appropriated for the purpose of eliciting critical reactions to researchers' accounts of Others' worlds. Ralston (1988) suggests that the use of terms culturally inscribed in one culture, to describe behaviour in another culture often reveals much about the researcher and little about the people who are supposedly the focus of the study. Bevan-Brown (1994) supports this analysis talking of how Maori understandings of disability are tied to culturally inscribed concepts. Operationalising Lather's third suggestion and eliciting the considered reactions of the people for whom research projects are intended to be emancipatory, might illuminate such culturally inscribed gaps in research dialogues.

Ralston's critique of the ways in which the lives of Polynesian women are interpreted in mainstream sociology, centres upon the problem that established disciplinary methods and exposition continue to obscure the realities of these women's lives. Ralston's critique can be appropriated for the purposes of disability politics. New research designs, and research in which existing research is analysed by a group similar to the original 'subjects' of the research, for example, could be legitimated on the basis of a critique such as Ralston's.

The principles of: providing an environment that invites critical reactions (Lather, 1991), power sensitive conversations (Haraway, 1988), deconstructive textual practices (Opie, 1992, 1992a), and the re-working of existing data and analyses (Ralston, 1988), are aspects of eliciting participants' considered reactions to experiences of being researched. If people are not experiencing research as emancipatory then finding out why is a good way to make sure future research is conducted in a more appropriate manner. As discussed in the following chapter, encouraging the participants to critically evaluate my interpretations of their lives, is a major factor in the design of this project.

Lather's fifth suggestion, and a major theme in her book, is that critical enquiry should stimulate a 'self-sustaining process of critical analysis and enlightened action' (Comsock, 1982:387 in Lather, 1991:64). Lather's emphasis upon dialogic and reflexive research methods reflects this concern. She suggests that the researcher join the participants in a 'theoretically-guided program of action over an extended period of time'. If dialogic interaction is achieved then the

world views held by both ‘researcher’ and ‘researched’ will be challenged. Repeat interviewing and the continuation of the project over a period of time in order to stimulate reciprocity (Oakley, 1981, Lather, 1991) feature in the research design discussed in this chapter. The preceding interpretation and critique of Lather’s five steps informs and guides this project. Critiques of existing research practices including the one described in this chapter are an important and on going part of this process.

Conclusion

I have argued the need to undertake politically engaged critical research; the need to recognise unequal power relations in the research process; the need to search for ways to work more collaboratively in a manner which encourages reciprocity; and the benefits of valuing rather than ignoring or denying difference.

A goal of this study is to destabilise the role of the researcher so that a dialogic interchange becomes the norm and monologic interviews need to be carefully documented and explained. Methods that demand reflexivity, stretch methodological parameters, and make collaboration an integral component of the method, feature in this study. In the interests of justifying such choices of method to a wide range of people the methodological parameters of this study have been rigourously defined and defended. The practices involved in establishing the validity of the research are intimately linked to this process of justification.

The participatory research model discussed in this chapter is one way in which we might challenge sexism, ableism, and the social relations within which disability is currently constructed. Morris’s (1991) ‘Us’ and ‘Them’ dichotomy works well as a critique of current practices. But we also need ways for people with disabilities and non-disabled to come together to work for social change; to find ways to achieve common political outcomes. hooks (1991) suggests we need to work through rather than deny our differences and move beyond this to understanding. She writes:

when women actively struggle in a truly supportive way to understand our differences, to change misguided, distorted perspectives, we lay the foundation for political solidarity... [This] solidarity requires

sustained, on going commitment. In feminist movement, there is need for diversity, disagreement, and difference if we are to grow (hooks, 1991:40).

Chapter Four

The Story of the Method

Methodological Issues

This study poses questions about the lives of women with disabilities considered from within a feminist postmodern framework. The purpose of this study is to research the lives of women with disabilities, from the perspective of women with disabilities. It can be argued that this goal is inhibited by my non-disabled embodiment. It can also be argued that in speaking for women with disabilities, which as I re-tell their stories, it is impossible for me not to do, I silence the voice of the Other¹.

These are important and valid critiques, and with these critiques in mind I wish to acknowledge my biases and my partial interpretations of the ideas and stories that inform this study. I do not seek to become the dispassionate, unbiased, neutral researcher who is merely a conduit, through which the ideas of women whose identities are different from my own, flow. Rather, I want to write myself into the research, in the sense that the lens through which I see the world is self consciously displayed. This strategy is designed to move the research to an interactive level of interpretation and to forestall a situation where the authorial voice of the researcher eclipses the voices of the participants. In the disability community, where experience and identity are primary determinants of research validity, the degree to which the participants are treated and presented as 'speaking subjects' determines the value of the research.

In this particular postmodern moment, when disabled identities serve the function of providing a rallying point for political action, the categories disabled and non-disabled are useful signifiers or categories of analysis. However, it could also be argued that, in employing these categories this study maintains binaries between disabled and non-disabled identities. Given that this study is designed to destabilise the binary between non-disabledness as the norm and disability as Other, I do not wish to unproblematically reinscribe these binaries. An amalgam of multiple and various subjectivities combine in the production of this text. The contradictions inherent in employing categorisations based on binary oppositions come to the fore on numerous occasions throughout the study. A case in point is that the research participants in this study, apart from the researcher, all have disabilities. However, the subject position 'person with a disability' is not always the position from which the research participants choose

¹ See previous chapter for a discussion of this.

to speak. One participant expressed concern that I had ‘gone on and on about disability’ in her Life History when it is not a major defining feature in her life, nor something which she dwells upon. Another expressed a wish to be asked for opinions on something other than disability, for a change. This study is set within a framework designed to encourage multiple and various voices to speak to one another and to Others. Rather than seeking to represent the ‘one’ ‘true’ view of women with disabilities, this study brings together a variety of voices at times unified, at times argumentative and dissenting.

Set within a framework designed to gather the complexities of multiple, various and competing voices the method utilised in this study seeks to achieve three main aims. First, to look at the gaps between the myths of disability and the everyday lives of women with disabilities. Second, to make links between feminist and disability politics, intended to be beneficial to feminism and disability politics. Third, to develop a participatory research method (Lykes, 1989, Reinharz, 1992) in which the subjects of the research share in directing the form and content of the research.

An Overview of the Method

When searching for an appropriate methodology, the problem of finding one sensitive to the workings of power was a primary concern. With this in mind, my theoretical research was concentrated in the following areas: Life History methodology, ethnomethodology, participant observation, discourse analysis, Foucault’s archaeological and genealogical methodologies² and feminist postmodern methodologies. Aspects of these various methodologies influence this study, however, the final product is primarily an amalgamation of Life History methodology and feminist participatory research methodologies.

In the interests of mediating the relations of power, inherent in the relationship between the researcher and the participants, a multi-layered research method is utilised in this study. Strategies, designed to redress the balance of power in the research process, such as repeat interviewing, encouraging the participants to comment upon their own and others’ stories and analyses, and the sharing of my theoretical analysis of the Life History interviews, were utilised.

² Especially the idea of ‘an ontology of ourselves’, or the question of ‘what is our present?’ (Foucault, 1988:95). These ideas are discussed in Chapter Two.

The formal part of this research method is divided into two stages. The first stage of the research is a Life History project. The second stage is an indepth follow-up interview constructed on the basis of the issues identified as important or major from the Life History data. A discussion of my analysis of the Life History research data, including themes and strongly stated single issues and a theoretical analysis of these issues, comprised the major component of this interview. In addition to these formal discussions, telephone calls, discussions over lunch, meetings with participants to return completed Life Histories, help with university assignments, accompanying participants to other cities as a carer, and chance meetings in the street have informed the research in various ways.

Reciprocity

In 1981, Oakley questioned the necessity of objectivity required in traditional research. Her critique is aimed at the heart of traditional research: the neutrality of the researcher, role differentiation between the researcher and the interviewee, the conceptualisation of the interview as a one way process and the preoccupation with statistically comparable data. Oakley proposed that the requirement of objectivity leads to the objectification of the interviewee.

The struggle to legitimate forms of research that do not conform to traditional research norms continues. A wide variety of strategies for subverting the process of objectification are suggested in feminist literature; much of the debate is directly relevant to issues around reciprocity. Opie (1992a) talks of the narrow and objectified function as data accorded interviewees in traditional research practice. Opie's interest in reciprocity also stems from the 'subject-become-object'³ status women are assigned in traditional research studies. The importance of the concept of reciprocity lies in the potential it holds in terms of empowering the research participants, and searching for new ways to legitimate and make audible previously silenced voices. Reciprocity can be set up, in opposition to objectivity, as a principle on which to claim the validity of alternative methodologies. Feminism, in all its multiple, various and contradictory guises, continues to struggle with issues of objectification in the research process.

³ A discussion of the subject-become-object status research participants are often assigned, is provided in Chapter Three.

Achieving reciprocal arrangements in a research context involves giving something back to the research participants. This involves more than not treating them as data, returning transcripts of the interview, offering payment, or giving gifts. Reciprocity includes giving up - or allowing participants to take - some of the power traditionally accorded to the researcher. As such it is a challenging aspect of the quest to find new ways of doing feminist research. The issue of reciprocity is addressed in four main ways in this study. First, through returning the Life Histories to the participants. Second, by listening to participants, hearing what they are saying and encouraging them to speak. This involves sharing my own experiences and knowledge. Third, by being available outside of the role of researcher, helping with university assignments for example. Fourth, by actively encouraging participants to take a role in the research, and defining my role in terms of their needs/desires/expectations.

Feminist principles aside, if I had come to this research as the traditional researcher, some of the women in this study would have kicked me straight back out the door. Being over researched, having interview material misquoted, and never hearing from interviewers when the research is finished, are some of the reasons for this hostility. The decision to take part in the research was, for some of the women in this study, politically motivated. 'What are we going to get for being part of the research?' is a question I was asked (albeit teasingly) at one access interview. Although I did not answer the question quite as articulately as I have here, she must have been satisfied with the answer as she agreed to take part in the study.

In terms of reciprocity, the most obvious and tangible component in this study is the Life History as a completed document. Although I do not know the fate of all the Life Histories, participants have put the completed documents to a variety of uses; to send to a friend; to save for relatives to read at a later date and to use as a component of a curriculum vitae.

In one case, returning the Life History to the participant inspired her to take a greater part in the research. Initially, she set aside an afternoon for the Life History interview, indicating that this was all the time she was prepared to give to the Life History phase of the research. Although this does not fit with the principles (or my preconceptions) of multiple in depth research interviews, I did not want to miss out on her story, so I agreed. Emerging ideas in feminist research practice suggest that eschewing standardisation in format allows the

research question, not the method to drive the research forward and encourages creativity (Reinharz, 1992). This principle is clearly demonstrated in the case of this particular participant. The completed Life History was returned to her at work. After reading it she said, 'wow you've really listened to me... this is the first time I've had feedback in all the times I've been researched'. Later in the conversation she said, 'that was really important what I said to you out there about how you've really listened. Usually people get it wrong'. We immediately carried out another Life History interview.

Listening, hearing what is being said, and encouraging dialogue are important components of reciprocity. Hearing other people's stories involves being sensitive to the research participants, learning to choose the appropriate moments for interactive strategies such as self disclosure, silence and encouragement. Answering questions and sharing knowledge and information is another important aspect of this process of reciprocity. Sharing information serves the double function of giving something tangible to the participants and fostering dialogic exchange. The timing and context of interactive strategies is key.

In sharing the intimacies of their lives with the researcher, participants make themselves vulnerable. Self disclosure on the part of the researcher, that is making herself vulnerable, can be conceptualised as a strategy by which reciprocity might be achieved. As with the sharing of knowledge, self disclosure is an aspect of dialogic exchange. However, self disclosure at an inappropriate moment can be as silencing or intimidating as the non-committal attitude advocated in traditional research. Although radically different from the 'neutral' stance of the traditional researcher these strategies can be seen as being part of relations of power or as reflecting power imbalances. Self disclosure is not always a de-objectifying and power sharing move. Too much self disclosure in the interview context and self reflexivity in the finished document can reveal more about the researcher than the research subjects: one of the criticisms of traditional research. While I have attempted to keep these issues in mind the degree to which I achieved my aims can only be assessed by the research participants.

Being available outside of my role as researcher was a mutually beneficial strategy in the research process. This involved a wide variety of activities from going for a walk with the participant and her dog, to help with university assignments and trips to other cities. Other social contact with participants

outside of the research has also informed the research. Some of the harshest and most insightful critiques of the research have occurred in these non-research oriented settings. Requests to use material discussed in social settings were not always granted. However, I believe that these exchanges - 'can I use this?' and a corresponding 'no' - are an important part of the research process, particularly in the context of developing reciprocal relationships.

Having talked about wanting the research to be from the perspective of women with disabilities and inviting comment and critique, a small and effective means of introducing participants to the concept of taking an active role in the research is the choice of their own pseudonyms. However, this small task is also a point at which the tension between taking the role of the researcher and encouraging participants to direct the research comes into play. The points at which this tension occurred included needing to convince some people a pseudonym was necessary and in one case deciding to use more than one pseudonym.

Conflict between taking control of the interviews myself and encouraging participants to contribute continued throughout the interview process. This was particularly evident with regard to the interplay of what the method suggests is an appropriate strategy and participants' desire to be treated as the traditional research subject. Utilising a feminist postmodern framework, in which we move away from binary conceptualisations of what constitutes 'good research', allows us to privilege reciprocity at the expense of uniformity. Participants' differing commitment to the project in terms of time becomes part of the methodology, rather than a cause for concern. Thus the researcher can come to the research on the terms of each individual participant, rather than not including the participant because she does not fulfil the requirements of the study. The participant who was not interested in doing multiple interviews is a case in point. Prioritising the principles of multiple in depth interview strategies would have silenced this woman's story. Prioritising reciprocity within a postmodern feminist framework means that her preferences are respected and her story is told. This directly opposes the methodology of traditional research in which uniformity is key, or even a feminist framework, where a participant's desire to be treated as a traditional research respondent might be conceptualised as unenlightened or 'false consciousness'.

Undertaking qualitative research within a feminist postmodern framework allowed me to stand outside my preconceptions of what constituted an appropriate role for a researcher, and informed my decision that collecting

information in a manner participants feel comfortable with is as important as maintaining a standardised stance as the researcher. This decision was strengthened by a realisation that, in defining my role as researcher and putting boundaries on the amount of time they were prepared to invest, participants were asserting control over the research process. Another point to which I did not give enough consideration was that my idea of the 'best' way to conduct research might be extremely uncomfortable for participants who wish to be treated as traditional research subjects. It became clear that the 'best' way to encourage one participant in particular to contribute and to make her feel comfortable, was to ask lots of questions. This contradicts the ideal of participant directed Life History research followed in this study. Although my input into this particular Life History was more directive than I would have liked, a fuller picture of this woman's life was gained, and she began to enjoy the interviews.

Questions about conflict between the objectives of the research and the requirements of the research were reflected upon in supervision sessions. In this case the question of 'what I... am for her?' provided a framework within which such questions should be answered. Utilising a methodology that encourages sensitivity to diversity enriches the research, in that it allows the collection of stories that might be lost under a more rigid methodology.

Ethical Issues

Ethical issues such as reciprocity are intimately tied to the utilisation of a politically engaged, feminist theoretical framework and to the principle of avoiding appropriation of the voice of the Other. Ethical issues were addressed with participants via discussion, an information sheet, and consent contract⁴. Participants were assured that they retained control over the use of the transcripts of the interviews, and that they retained the right to withdraw from the study at any time.

When I began this thesis, I planned to include the Life Histories as complete documents in the finished thesis. One participant requested that her Life History not be included in its entirety, and that instead only excerpts be used from it. Another participant informed me that she had told me things she would not tell anyone, especially about 'the abuse and the sex'. Even her flatmates did not

⁴ The information sheet and the consent contract are provided in Appendix One.

know about the sex because her partner put her back to bed in the morning when she got home. In the interests of preserving anonymity I have included excerpts from all the Life Histories and not included them in their entirety with the finished thesis. Instead, some of these Life Histories will be lodged in the Alexander Turnbull Library, Oral History Archive in Wellington⁵.

Multiple in depth research practices are likely to encourage self disclosure. Consequently this research was undertaken with the understanding that any problems that arose in the course of the research would be referred to an appropriate social service, or counsellor. Participants were informed of this potentially painful aspect of the research and that if, this was the case, they would be referred to an appropriate person. The participant who was abused sought counselling.

Originally, a group interview was to be offered after the Life History research. The ideas of the group were to be shared with the participants who did not wish to attend the group interview at a later date. Participants who had attended the group interview were to be contacted later in case they had ideas they had not wished to share in a group setting. However, on completing the Life Histories I considered that a group interview was not appropriate. The decision to exclude the group interview was made on the basis that the disability community is smaller than I realised at the onset of the study, and a face to face meeting compromised the anonymity of the participants.

The Participants

This study, with six women with physical disabilities, took place over a four year period. The Life History and follow-up interviews were conducted within a two year period. The women were gathered informally through personal contact, networks of friends and colleagues, and acquaintances. In the interests of the privacy of the participants the disclosure of personal information has been kept to a minimum.⁶

⁵ Access to the Life Histories will be restricted through the use of a time bar and/or by requesting the permission of the participant.

⁶ This decision was made in conjunction with the research participants.

Pseudonyms

The names of the participants and other people mentioned in the research have been changed in order to preserve the anonymity of the participants. Pseudonyms were chosen by participants themselves. The term 'the participant' or the phrase 'one of the participants' is used on occasions to confound clues to identity.

A Description of the Participants

The participants were of various ages ranging from their early twenties to their fifties. All the participants were either employed or studying. Five participants lived in an urban setting, one lived in a small town. One participant is Maori and one has a child. At the time of the study, all the participants were single, four had tertiary qualifications and although all lived in their own homes, three had lived in institutions, and all had regular home help and/ or carers.

Relevant Disability Related Details

An overview of the various disabilities the women in this study have is relevant in terms of the construction of disabled identities. All the women in this study have disabilities that were observable at the time of the study. Some disabilities are congenital, some are late onset, some fit within more than one aetiological category, none are the result of injury. The physical manifestations of the various disabilities have changed over the course of the women's lives.

Time

The time taken to accumulate the Life Histories and follow-up interviews is another feature of the research. Although I initially had an idea that the Life Histories should be completed within a certain time frame, it was soon apparent that the process could not be rushed. Sometimes it was necessary to wait to go back to the participants, as they had other projects or commitments. One participant needed time to grieve for the loss of someone she loved before returning to the research, and another spent repeated periods of time in hospital.

Enabling People to Speak

Enabling people to speak is a function of the researcher's job when conducting qualitative research. Although some of the women in this study are what could be described as loud, opinionated, bolshy and proud of it, others are more reticent. Speaking out on 'public' issues is second nature for some of these women. However, speaking about sensitive or 'personal' issues is different from speaking about 'public' issues, and is something that most people find difficult. Providing a safe and supportive environment for women to talk about personal issues, or express opinions about political issues, is one way in which participants were encouraged to speak. I found that keeping silent, being encouraging and asking questions, rather than offering comment were the strategies that the women in this study seemed most comfortable with when sensitive issues were at stake. The confidentiality of the interview situation is another factor in encouraging people to speak.

The Life Histories

In the first stage of the research the participants were either directly approached by me, or contacted by the people who initially suggested them. The women contacted through a third party were then telephoned or visited by me. During this initial contact an 'access' interview was arranged.

In the 'access' interview a short description of what the research entailed in terms of time commitment and content was provided. The research process was explained to the women and they had the opportunity to question and comment upon the study. I explained that although in the Life History interviews I did not have set questions to ask, my questions would be influenced by a feminist standpoint.

An information sheet⁷ explaining what the study involved and identifying issues regarding confidentiality was provided at the access interview. I explained that I was using a feminist framework and that I was trying to produce something that was not just the researcher saying, 'this is how your lives appear to me and this is how I think things could be done better'. It explained that although I was doing this to obtain a qualification and in that sense the research was mine, that

⁷ See appendix 1 for a copy of the consent form and information sheet.

they had some control over the process as well as the content, and that I was interested in their challenges of me and the research. The women who wished to participate in the study were then provided with the consent contract. This consent contract was signed at the beginning of the 'Life History' interview process by the participant and by me. Of the women I approached only one did not wish to take part.

The consent interviews were conducted either at the participants' place of work or in their homes. All the Life History and follow-up interviews took place in the participants' homes except for one impromptu interview undertaken in the work place. This participant initially set clear boundaries around the time she was prepared to spend on the project. However, reading her Life History inspired her to participate further.

The Life History interviews were recorded in hand written form and transcribed by the researcher as soon as possible after the completion of the interview, usually within a 24 hour period. The decision to write, rather than tape record the interviews, was made on the basis that editing of the text takes place naturally in this process. Writing up the transcripts immediately after the interview is an important part of this process as I rely on my memory of the interviews in the construction of the Life Histories. This writing and editing process and the power accorded the researcher to ask questions to keep the interview moving have the potential to give the researcher power over the content of the Life History. However, returning the typed transcripts to the participant after each interview and at the completion of the interview for additions, subtractions or alterations subverts the power inherent in these practices.

The Postmodern Moment

The Life Histories are not presented to the reader as pure and untainted stories representing the 'truth' of the research participants. A number of different factors impacted upon the production of these texts. These included the diverse and various political interests of the research participants: disability activist, feminist, socialist, libertarian and so on. Additional influences such as the researcher's feminist interests and the participant's response to this, also impacted on the texts. Recorded at a different time or in different circumstances the Life Histories might tell different stories. This acknowledgement of the

constructedness of the Life Histories does not make these stories any less valid, it merely contextualises them as documents and locates them as the product of a particular moment.

Timing

Time is an important factor in relation to inequitable power arrangements. The time participants have to consider changes and the number of opportunities given to alter the text influences the dynamics of power relations. In this study I was concerned to give participants time to consider and implement changes at their leisure; consequently typed transcripts were returned prior to the next interview session⁸. Some participants wrote changes in as marginal notes, others narrated the changes to me verbally, another occasionally restructured sentences as we went along. Returning complete drafts of the finished Life History gave respondents a second opportunity to implement changes. This process of narrating and re-narrating, writing and re-writing is a major strength of the Life History method and a major factor in my choice of the method.

The interviews were structured in the following way. The interviews began with a discussion of the transcript returned in the previous session. The interviews ranged from one to three hours in duration and were completed in two to eight sessions. The two shorter Life Histories were narrated within a period of four to five hours. This consisted of an initial longer session, in which most points covered in the Life History were addressed, and a further fleshing out of the material at the subsequent interview. The remainder of the Life Histories were recorded in fairly even blocks. The time spent to complete each interview was directed by the time each participant was willing to commit to the project. One participant requested that I ask specific questions during the course of each interview. Most participants were happy to talk with a minimum of prompting. Each participant has a copy of their finished transcript.

⁸ In an earlier Life History study undertaken as part fulfilment of a post-graduate diploma in Women's Studies, the previous session's notes were read through by the researcher and the participant at the beginning of each successive interview. This was a time consuming exercise which left little time to collect further material. The participant and I abandoned this method in favour of practice used in this study of returning the notes from the previous session before the next session and reading through the changes rather than the entire transcript.

Researcher self disclosure was a part of the research method utilised in this study. This is an aspect of the decision to locate myself away from the position of the traditional neutral unbiased researcher. In my experience commenting upon the participants' stories and sharing my own experiences, enriches the relationship between the researcher and the participants and thus the Life Histories. This self disclosure moves the research closer to achieving the goal, suggested in Chapter Three, of creating a fundamentally dialogic relationship between the researcher and the participants.

The flexibility of the Life History method allows the researcher to respond to the needs of the respondents in appropriate ways. A variety of information can thus be collected using methods sensitive to the needs and wishes of the respondents. The methods of soliciting information are not standardised in the same way as a traditional structured interview in which the researcher seeks to remain impartial. However, this does not inhibit the production of an intelligible set of documents. Utilised as a method of collecting information useful for conducting a study relevant to the lives of women with disabilities, I feel this method worked successfully.

The Follow-Up Interviews

The Life History interviews provided an opportunity for the participants to speak about what they considered to be important in their lives. The follow-up interviews were a forum for discussion of these topics. A semi-structured interview guide and a tape recorder were used in the follow-up interviews. The changes of method and research instruments reflect different priorities at the respective stages of the study. My role as researcher changed in the follow-up interviews, from primarily listening, commenting and prompting, to questioning and explaining. My part in the research was more active than in the Life History interviews, I invited dissent and discussion; rephrased questions to provoke answers; expressed excitement and agitation; and questioned answers. The tone of the interviews was generally more conversational than the Life History interviews. We found ourselves discussing books, movies, politics, art and relationships.

The familiarity engendered in the process of the Life History interviews and, in some cases, the continuing social interaction with the participants made this style of interviewing appropriate. Each interview began with an explanation of

the methods by which the interview guide for the second set of interviews was constructed. The main points covered in this introductory explanation were: first, that the material for the interview guide came primarily from the Life Histories and dealt with issues that I felt had been most strongly emphasised. Second, an explanation of the purpose of the theoretical component of the interview guide was offered. The theoretical analysis comprises a major part of the interview guide and was included to give participants an opportunity to comment upon my theoretical analysis of their lives, and to encourage them to share their own theories and analyses. Comment from the participants on this theoretical material was strongly encouraged. Third, I explained that I wanted the interview to take a conversational form, because this encouraged disagreement and discussion, and that we were bound to have different opinions because of our personal and political differences. This explanation was a necessary part of providing the tools and opportunities for critical reflection and analysis, thus providing 'the possibility of jointly creating a more critical understanding of a given reality' (Maguire, 1987:38). I emphasised that a major objective of this project was to give women with disabilities a forum to express themselves, and that disagreement and discussion were bound to be an important aspect of this.

A central concern in this study is not to speak for women with disabilities, rather, to provide a medium through which women with disabilities can speak. Moving away from researcher directed interview techniques, and encouraging participants to actively direct the course of the interviews and the research, is a major part of this. In retrospect, I think the aims of the research could be more explicitly stated at the 'access' interview, particularly in terms of a description of traditional research techniques and the ways in which participatory research methodology differs. This may have changed the role participants wished to take in this study, particularly in terms of wanting to take a more active role in the research than that dictated by traditional research methodologies.

The Follow-Up Interview Guide

The questions, statements, and comments included in the follow-up interviews were generated in a variety of ways. Reading through the Life History transcripts I highlighted issues that participants had stressed and themes that began to appear. Footnotes made during the process of writing up the Life Histories also contributed to this initial stage of the analysis. After reading through and refamiliarising myself with the text, I re-read the texts, organising

the material into categories. The word search function on the computer was used to check for references to themes and issues. The word search function on my computer highlights a word or group of letters. For example, comments about how the health system works with regard to the women in this study, are organised under the heading 'medical model'. Word searches undertaken in this case included:-medic, health, profess, sick, doctor, ill, physio, gyno, psych and surg. These word searches augmented the information gained from reading the transcripts, but did not significantly change the opinions I gained from reading the Life Histories.

The medical model example also illustrates the point that my initial categorisation of information did not always fit with the points being made by the participants. The literature suggests that the medical model and health professionals generally are viewed negatively by people with disabilities. Rather than a straight forward critique, the Life Histories reveal a more complex set of relationships and attitudes, both positive and negative. I would have expected to ask (and would have asked, had I not undertaken the Life History research) questions about doctors and health professionals. Instead, in the interview guide the category 'medical model' translates into a more complex set of questions about other peoples attitudes, privacy, access and sexuality.

The interview guide is constructed on the basis of the points most strongly emphasised in the Life History interviews. This includes but is not limited to the development of themes. My decision to include single issue items was made on the basis that some concerns are less socially or culturally acceptable than others and are therefore harder to speak about. (It is easier to speak frankly of the consequences of employment discrimination, than it is to speak about experiences of being denied information about sexuality by a doctor. Employment discrimination is legislated against and generally accepted as undesirable, while being assigned a-sexuality can be regarded as an unpleasant yet personal experience.) Theoretically this corresponds to the Foucauldian idea of hegemonic and counter hegemonic discourses being imbued with relative amounts of power⁹. Oakley's (1981) critique of traditional research paradigms (discussed above) is also relevant to this decision to include single issue items as well as themes. In searching only for themes, we may be pursuing generalisable

⁹ The terms hegemony, counter hegemony and power are discussed and defined in Chapters One and Two.

outcomes at the expense of exposing more nuanced and radical critiques of existing power regimes.

Time Frame

These second stage interviews took between an hour and a half and three hours to complete. In order to facilitate an interactive dialogic exchange between the participant and the researcher the interviews were taped. The Life History interviews were designed to encourage participants to speak on any subject they considered important. The researcher's role in this process is to encourage the telling of stories in a supportive context. The challenge is to hear what is being said, even if the speech is contrary to what we expect or want to hear, perhaps even hostile or challenging. The process of glancing at the participant and back at the page, that occurs naturally in the course of transcribing an interview by hand, encourages the participant to speak and the researcher to remain silent. This was appropriate in the Life History interviews but is not appropriate or feasible in interviews such as the follow-up interviews where, the researcher is required to engage with the participant.

Interview Structure

All the questions in the interview guide were addressed with each research participant. The interviews did not always progress in the order suggested by the interview guide. Participants often moved across a variety of theoretical and substantive material in answering a question. In order to encourage a conversational style, priority was given to addressing topics in the order they came up. New questions and new approaches to the questions suggested in the follow-up guide, were forwarded by the participants throughout this process.

Ideas that had arisen in the previous follow-up interviews were brought directly into the consecutive interviews with other participants. Although this changed the nature of some questions, I believe this process contributed to the quality of the research. For example, one of the questions is about people's expectations of women with disabilities. In the Life Histories it was suggested expecting too little of someone, because of their disability, led to people not achieving as much as they could. The statement put to the respondents in the follow-up interviews was, *'other people's expectations, of what people with disabilities*

are capable of doing, can be a major source of frustration for women with disabilities'. Participants' initial responses to this statement centred on too much being expected of them, and the material aspects of having a disability being ignored. In subsequent discussions of the origin of the statement and previous participants' responses to the question, conforming to non-disabled expectations - of what was achievable in a day, for example - emerged as a far more pressing issue.

The structure of these interviews was also influenced by the research participants' various educational backgrounds. Three of the participants had some familiarity with postmodern feminist theory and three did not. I found the process of explaining and discussing my theoretical material with people for whom it was new or unfamiliar, enjoyable, challenging and at times embarrassing and frustrating. Reconceptualising the theories I intended to use to analyse the research was a learning experience for me, especially when it was evident from people's responses or reactions that I hadn't explained myself very clearly. The process of having to think quickly of another way to explain myself could be described as a fertile struggle. I was not always successful in getting my point across; nevertheless I often felt that a connection between theory and experience had been made.

Making Sense of What Was Learned: Analysing the Follow-Up Interviews

Fertile struggle is a characteristic of this study. Finding a method suitable for the purpose of analysing the follow-up interviews was one of the most challenging of these struggles. The current crisis of interpretation in the social sciences necessitates careful and strategic methods. Discarding traditional qualitative tools, such as content analysis, on the basis that such analytic strategies are not flexible enough, I considered that discourse analysis (Gavey, 1989, Denzin, 1994, Potter and Wetherell, 1994) might prove a suitable analytical tool for this phase of the research. Further engagement with the literature revealed that in discourse analysis, the general is subsumed to the particular. Attention to the details of the text is a strength of this methodology, but the absence of a means of forming an overview of the more generalised or non-specific aspects of the text can make it unsuitable for the purposes of this study. A practical analytic style, flexible enough to oscillate between detailed attention to text and the need to develop a feeling for the more emotional/affective aspects of the study as a

whole, was needed. Gradually a plan to use a colour thematic analysis developed. The specificities of the ways in which the analysis was carried out are described below.

My analysis of the difficulties inherent in establishing a professional relationship with carers is utilised to illustrate the appropriateness of the method. The difficulties of establishing a professional relationship in the context of a job that requires intimate contact, and whose very subject is the care and welfare of the person for whom the carer is working, are complex and subtle.

Henrietta: Because it's such a closed community around here and caregivers, like I find, that people aren't even often aware that they're breaching confidence. And I'll know, oh yeah that's such and such they're talking about, and they aren't even aware. And sometimes I'll be good and let them know that I know that person and sometimes I won't be good and I'll listen to the gossip. Ha, ha, ha, ha, ha... And I guess the other thing is to know how that information is used.

Henrietta's comment covers the issue of negotiating relationships; at the same time it highlights the related issue of opportunities for abuses of power/knowledge. I needed a methodology that allowed me to use the whole passage in one context and to take the last sentence in isolation in order to analyse it more fully.

And I guess the other thing is to know how that information is used.

My written analysis of the follow-up interviews began during the transcription of the tapes. Ideas were recorded in the form of footnotes. These footnotes were later incorporated into the colour thematic analysis. The next step in the analysis involved reading the interview transcripts and listening to the tapes, in order to familiarise myself with the texts. I then re-read the texts, marker pens in hand, looking for themes and dominant messages. This re-reading revealed not only substantive themes in the material, but also many instances of contradiction and a significant use of irony. Marginal notations, in broad strokes of coloured highlighter, were used to mark these initial categories. The transcripts were first organised into three categories reflecting the main theoretical themes pursued in the study; identity, the body, and the self. Interestingly this process produced three roughly even sized piles of notes. This initial sorting process also revealed participant's interests in the various theoretical categories.

In this initial stage, classification of material - especially when there was no obvious link between a passage and the body, identity, and the self - was done by returning to the theoretical chapters. For example, a passage that clearly demonstrated panopticism, but was only loosely connected to the body might be classified primarily under 'the self', because of its links to the notion of docile bodies. The tri-colour coding system ensured that alternative ways in which a single passage might be used were explored further along in the analysis.

The next step involved disregarding the initial classifications and beginning colour coding according to developing themes. Themes emerging from the data were originally categorised under 18 broad categories and a variety of sub-categories. The interview guide acted as a structuring mechanism in some cases. For example, other people's expectations of people with disabilities developed as a very clear theme, directly from the interview guide. In other cases, the interview guide acted as little more than a point of departure. Questions addressed in the interview guide, such as questions about carers and flexibility, and issues about the need for carers to have a commitment to the job and an understanding of what is required, developed far in excess of what comments made in the Life History interviews led me to expect.

Problems, such as running out of colour options and forgetting what colours signified, have been identified in colour thematic analyses¹⁰. Two strategies were developed to rectify these problems. First, felt pens were used to distinguish categories. Using a different kind of marker ensured a wide variety of colours which enabled me to clearly see what was happening with the original highlighted categories of identity, the body, and the self. Second, in order to facilitate quick referencing, a register of colour codes was made. The transcripts were cut up and arranged in piles. A variety of different ways of organising the transcripts were trialed over the course of this analysis.

Unused sections of transcripts were kept in a separate folder and were returned to from time to time. This allowed comments that had initially seemed irrelevant to establish themselves as the analysis developed. The transcripts were then

¹⁰ Personal communications with Jenny Carryer (1996) Department of Nursing and Midwifery, Massey University and Lee Coombs (1996) Psychology Department, Massey University, PB 11-222, Palmerston North, New Zealand.

minimally edited for the purposes of enhancing readability. Identifying features, characteristics and figures of speech were also removed.

My analysis of the fears, hopes, dreams, aspirations, theories and analyses shared with me by the participants over the course of the study is presented in Chapters Five, Six and Seven. This is followed by a reflexive analysis of the research practices utilised in this study in Chapter Eight.

Conclusion

The story of the method could continue up until the final production of the final draft of this thesis. My concern in concluding this section is to acknowledge the enormous part the participants played in shaping this study. Some of the participants continued their input into the study, in direct and indirect ways, until the final drafts of the thesis. I hope the story of the method of this study is part of an ongoing story towards progressively more collaborative methods of research.

Section Three:

Talking Through: Fears, Hopes, Dreams, Aspirations, Theories and Analyses

Introduction to Section 3

The Politics and the Ethics of Interpretation

I call making sense of what has been learned the *art of interpretation* (Denzin, 1994:500) (emphasis in original).

Interview data doesn't just jump into clear, precise, convenient categories; it slips, slides and shuffles its way, sometimes backtracking and trampling itself. Sometimes researchers coerce, constrict, crush and constrain the information. Sometimes we have a hunch that doesn't fit the data but we want to get our idea in there somewhere. Sometimes the data doesn't support what we know to be true because we didn't ask the questions in the right way. These issues fall towards the darker, unspoken side of the art and science of interpretation; that is, the politics and the ethics. The politics, ethics and validity of interpretative practices are difficult and tricky terrain.

Interpretations

It is difficult to pinpoint exactly where the analysis began in this study. While most researchers would not deny that the conception of the analysis of data begins well before the data collection point, traditionally the writing of an analysis comes directly after the data or results section. In this study it could be argued that analyses - particularly the participants' analyses of their lives, began before the study itself. For the purpose of the coherency of the thesis as a whole, I will locate the formal beginnings of the analysis at a point between the writing of the Life Histories and the formation of the follow-up interview guide. In the follow-up interviews the participants shared theories and analyses of their own lives and of the issues raised in the Life History interviews.

The following section presents the fears, hopes, dreams, aspirations, theories and analyses of the women who participated in this study. Most of the information in this section is drawn from the follow-up interviews. However, at times I have returned to the Life Histories or the interview guide for the follow-up interviews in order to better illustrate a point or describe its origins.

This study has its inception in feminist theory, particularly feminist postmodern theory. Feminist postmodern theory informs every phase of the research. My

choice to use this particular perspective reflects its ability to speak to the everyday, the general, the silent and the freely spoken, the public and the private, the theoretical and the substantive, as well as hegemonic and resistant discourses. The theory and the everyday merge, collide and mingle in this study which has been revealing in itself. The interrelationship between the opinions and beliefs of the various participants was also revealing. The interrelatedness of the participants accounts of their lives developed through the process of the Life History and follow-up interviews and in the context of my previous or subsequent relationships with some of the participants.

The problem faced in this analysis, as with any qualitative study, was what to leave in and what to leave out. The interviews, particularly the follow-up interviews, were rich with interesting and relevant data. Multiple possibilities existed for the organisation of this data. The categories generated from this data were systematically rearranged right up to the final drafts of the following chapters. Changes in my perceptions of the research findings, in light of the developing analysis, prompted changes to categories and themes.

As mentioned in the previous chapter, systems of colour coding were used to keep track of categories and themes. Originally the data was sorted into categories relating to the theoretical concerns upon which this study is self consciously grounded, that is, the body, identity, and the self. These categories were then temporarily set aside in order to let themes emerge 'naturally' from the text. Later these themes were reorganised according to the original three categories. This strategy was designed to prompt me to consider the ways in which a single passage might be analysed from a variety of alternative perspectives.

Acknowledging the ways in which the analysis evolves and responds over time to various stimuli is a function of the method used in this study. The analysis of the information shared with me, by the participants, over the course of this study is inextricably intertwined with the presentation of the research in the following three chapters. Trying to present this information in the more traditional format of data chapters followed by an analysis was not appropriate. Such a format would, to a certain extent, be artificial as it denies the role of the research participants in the analyses of their own lives and in the process of the development of the analysis.

The participants' contributions to this process of analysis can be located at various points throughout this document. These contributions began with the Life History interviews and continued throughout the follow-up interviews and in some cases beyond into less formal, but no less important, interactions with the researcher. Using the participants' own words to describe their perspectives precisely locates these contributions. As the writer of this document, my analytic framework develops throughout the text. In the following section my analysis both integrates and is integrated with these various aspects of the text. The follow-up interview guide, appended to this document, describes the preliminary interactions of theoretical material and substantive issues. The process of generating ideas and capturing issues, can be understood as a framework within which the thematic schema of this study developed.

The themes arising from the Life History and follow-up interviews are presented in the following chapters. The words of participants themselves are used whenever possible. This serves the dual purpose of substantiating the themes and of revealing the voices of the participants. This is part of the process of ensuring the research remains firmly grounded in the everyday realities of the participants. The participants describe what it feels like to have a disability in a non-disabled world. They articulate a politicised understanding of many of the marginalising practices occurring in their everyday lives and the ways in which disabling practices are resisted.

The participants' stories suggest that the marginalisation to which people with disabilities are subject is experienced in a variety of ways and on many different levels. Many of the disabling practices identified in this study work equally effectively in relation to various aspects of the lives of the participants. For example, medical discourses on disability find expression in practices ranging from health research funding to the arrangement of furniture in doctors' offices. Resistance to the marginalising practices identified in this study continually returned to attitudes and popular misconceptions held by people who have no experience of disability or contact with people with disabilities.

Chapter Five is an analysis of the meanings, functions and uses of identity, and identity politics. Chapter Six considers the ways in which the attitudes and assumptions of non-disabled people impact upon women with disabilities and concludes with an analysis of the participants' views on privacy and sexuality. In Chapter Seven, factors which impact upon the participants' construction of

selves, particularly the aspect of requiring carers, are analysed in terms of relations of power and political implications.

Presenting the Follow-Up Interviews

Utilising a postmodern participatory research method, in which the participant and the researcher collaborate in the production of the text, demands attention to the context and construction of narratives. The position of researcher as ventriloquist (Fine, 1992), where text is presented as the pure and untainted words of the participant, is an untenable position. Moving to higher levels of abstraction (Mishler, 1992), representing the contours of the voice (Opie, 1994) and utilising conversation analysis techniques (Antaki, 1988), where orality is represented textually are presented in opposition to traditional research techniques where words are presented as if they unproblematically represented the complexities of voice. Although I agree with the movement towards more complex textual representations, I do not want to carry my analysis to a level of abstraction that denies the materiality of the text. Where, for example, what is being said becomes almost lost in the deconstruction of the text.

The textual practices followed in the written representation of oral text are described below.

Emphasis is indicated by the use of italics.

Exclamations, such as, hum,ah-ha, ha, and laughter or sighs indicated either as the sounds of the words or written in phonetic form.

'...' indicates a natural pause in the conversation but does not necessarily correspond to the beginning of a new paragraph.

'... ...' indicates an especially long pause in conversation.

'...' followed by a new paragraph indicates that the research participant has paused before moving to a slightly different train of thought.

A hyphen, between two words that would normally not be hyphenated, indicates that the participant quickly qualified or emphasised what they were saying without the expected pause between words or sentences.

[...] indicates that I have removed something/edited the text.

In addition, in the interview transcripts I refer to myself using my own first name.

Chapter Five

Moving Beyond Simple Deployments of Identity

Introduction

A significant component of this thesis addresses identity issues. The reasons for the emphasis on identity relate to both the theoretical and practical issues addressed in this study. My embodied difference from the research participants, conceptualised in the question of, 'what am I... for her' is one of these issues. Another reason for the significance of identity in this study, is the place identity holds as a construct, in both disability politics and feminist postmodernism. The third issue, related to both embodied difference and the concerns of disability politics and feminism, is the predominance of identity related themes in the follow-up interviews. These reasons make identity a suitable site for interventions between women with disabilities and feminism. Disability politics is at a point at which identity is claimed as an effective political tool (see for example, Oliver, 1990, Morris, 1991) while feminism, on the other hand, is at the point of questioning whether identity politics are politically expedient (see for example, Fuss, 1989, Schor, 1989, Morris, 1991).

Questioning the place identity holds with regards to political strategies has generated much debate within feminism. Debate centres on whether it is possible to reduce experience to predetermined, biological, social, or cross cultural constructs (Grosz, 1990, Soper, 1990, Yeatman, 1994). The question, of whether it is possible to claim that there is something essential or irreducible about having the body of a woman or having a disability, is discussed in Chapter One. This discussion does not conclude with any definitive answers. However, it is argued that meanings are attached to identities and that identities cannot be regarded as immaterial.

For the participants in this study, identity is certainly a material concept. Identity is a site at which a great deal of resistance to assigned subject positions is encountered. Challenges to non-disabled conceptualisations of disability surfaced continually in this study. Negotiating an identity outside of assigned subject positions is one aspect of this; refusing to take one aspect of yourself and let it represent your whole person is another. These issues were discussed with participants over the course of the study. Expressions of ambivalence and contradiction characterised these discussions.

Identity was taken into account throughout the research process. This involved beginning from the experience of the people being studied. Providing

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participants with opportunities to question and challenge me puts this principle into practice. On a personal level the participants challenged me on the basis of my identity. Questions such as, is it appropriate for a non-disabled woman to research women with disabilities? and challenges about why I chose physical, rather than intellectual disability were issued. Was it because physical disability is more socially acceptable? These questions challenged me in a variety of ways and were sometimes difficult to answer. My feminist identity and feminist interpretations of issues were not always welcomed by participants. *'I can tell you now I'm definitely not a feminist'* - was the strongest of these objections.

This study is founded on pre-stated feminist principles. Some of these principles such as writing against Othering, operationalised in practices such as beginning from the experience of women with disabilities are directly related to identity issues. Others, including paying attention to difference and diversity, and choice of research and interview practices are indirectly related. In keeping with principles and values established throughout the study, my embodied difference from the research participants necessitates reflexivity about identity issues.

Writing myself into the research, as non-disabled and therefore embodying difference, and as a woman and therefore same, both reinscribes and challenges notions of disability and difference. This meeting of feminist theories of women's embodied difference and the experiences of women with disabilities stimulates further discussion of identity issues. The first theme discussed in this section, picking one aspect of yourself and making it substitute for the whole, provides a clear example of this process. The second theme, an-Other perspective, looks at how disabling discourses are communicated and how people with disabilities insert themselves into such discourses. This theme explores issues around the discursive construction of disability as a deviation from the non-disabled norm. The third theme looks at the participants' views on identity itself. Issues around fashioning, claiming and resisting identity are discussed in this section. The final theme in which comparisons are drawn between disability issues and the concerns of more well established social movements is concerned with the political ramifications of a politics of identity.

Picking One Aspect of Yourself and Making it Substitute for the Whole

This theme emerged from my analysis of the Life History interviews and was subsequently discussed with participants in the follow-up interviews. Most of the participants had strong opinions on this issue. The following extract from Morag's Life History was used to stimulate discussion:

A major problem for Morag at the moment is losing sight of herself because of what is happening around her. 'As women irrespective of what is happening in our lives, we lose sight of our own beings'.

This extract was discussed with reference to Lorde's (1984) discussion of the problems associated with being constantly asked to pick one aspect of oneself and present it as a substitute for the whole person. From these discussions a consensus of opinion developed, that disability is not the only issue that people with disabilities are interested in and wish to speak about.

Putting the person back into discourses of disability is a primary aim of the disability movement (Kolucki, 1994). This movement is represented in the term 'person with a disability'. As Kelly suggested in the follow-up interviews: *people with disabilities, [is a] political term*, designed to change people's attitudes by shifting the focus away from the disability and onto the person. People with disabilities are more than the sum of their disabilities. It can be argued that requiring people with disabilities to constantly speak about disability undermines this basic tenet of the disability movement. Henrietta found the experience of constantly being asked to pick one aspect of herself and talk about it frustrating:

Henrietta: Yes, definitely. I'm finding that more at work where I've got myself stereotyped I think. Where I'm expected to go all around the different faculties and courses talking about disability issues. And it's like I can't talk about anything else. I've got no other skills at anything else but I can talk about disability. Anything that's got anything about disability. [...]

I think there's two parts to it as well the expectations bit. Apart from the fact that disabled people can't talk about anything else apart from

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disability. [...] The other side is that you either take the supercrip line where you have to be better than everyone else and can't just sort of plod along as a 'C' student or a 'B' student type routine... um, yeah, in order for people to acknowledge that you can actually do things... Or that people just don't expect anything from you.

Henrietta's analysis raises a further problem discussed in various contexts over the course of this study. The problem of over reliance on a small group of people to represent the perspective of people with disabilities falsely homogenises the experience of disability. The problems with politics and strategies that falsely homogenise the experiences of a diverse range of people are discussed by many of the authors in this thesis (see for example, Fuss, 1989, hooks, 1990, Irwin, 1990, 1992, Sawicki, 1991, Gibson-Graham, 1995). Encouraging someone to constantly speak about disability, and repeatedly choosing one person to speak on behalf of people with disabilities can contribute towards the maintenance of disability as Other. It can be argued that these strategies are grounded upon the assumption that the experience of having a disability is reducible to a singular and known category and are therefore ableist.

Objecting to being asked to pick disability as the major defining feature in their lives is also an objection to the world seeing them as 'other' and as Other than they see themselves. In the Life Histories, disability was identified as a major defining feature in the participants' lives. However, a variety of different identities were strongly claimed. Discussions about identity in the follow-up interviews revealed major resistance to non-disabled people's conceptualisations of what it means to have a disability. Resistance to being assigned an identity primarily on the basis of disability was apparent in many of the participants' comments:

Stacey: I wouldn't like to think they said the lady with MS. I'd hope they said 'David's Mother, Stacey Cargil'. I like to think that's how they spoke. As far as I know they do.

Kelly: [...] I think it's your attitude towards yourself and other people that highlights you as a person [...] You just go out there and do what you have to do. And, you know, show people that your disability doesn't influence you then it won't become an issue for them.

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In a conversation with Kelly¹ she commented that positive representations of people with disabilities are lacking in popular culture. *'Putting us in [Shortland Street] (a popular prime-time soap opera) as characters who are primarily there to be people with disabilities highlights our marginalisation and puts us on a pedestal'*. Misrepresentations and misconceptions are so common, that when someone does occasionally get it right it is regarded as a pleasant surprise:

Michelle: Disability is identified as a major defining feature in peoples' lives but an identity as a woman is also strongly claimed. Like, OK maybe for other [non-disabled] people you having a disability is the major defining feature but you're not just your disability...

Henrietta: Oh yeah absolutely... Or a fire hazard. That was the whole point of it in 'Grid Lock' I think. You know that passage about the fire hazard [...] and that was the whole identifying characteristic as somebody in a wheelchair. Not so long ago, she was a woman and she was seen to be attractive and um, you know people wanted her to go to clubs and bars, and all the rest of it. They were quite happy to have her spend her money there, but now she wasn't allowed in because she was a fire hazard. All this sort of thing. [...] For a guy who doesn't have a disability, he showed remarkable insight.

The participants' views on this subject are consistent with the movement within disability politics to put the person before the disability². The movement to put the person before the disability reflects a recognition of, and resistance to, non-disabled people's negative attitudes about the lives of people with disabilities. The women who contribute to Morris's (1991) book, *'Pride Against Prejudice'* speak of the many negative ways in which non-disabled people's reactions to the physical differences of people with disabilities, define and constrict their life choices. Discussions in this study reiterated the feelings expressed in *'Pride*

¹ This conversation took place after the completion of the 'follow-up' interviews. However, this is a subject that Kelly feels passionate about and she wished it to be included.

² Sullivan (1991) suggests that there is much debate over terminology in the disability community. The person with a disability label is not universally accepted as the most appropriate within disability politics. For example, Oliver (1990) suggests that the movement to put the person before the disability represents a denial of disability as an essential part of the self.

Against Prejudice' to a certain extent. Alongside this critique of non-disabled sensibilities, an expectation of, and hope for, better understandings exists. In the section below, the participants share their own analyses of a number of the discourses and practices operating in their lives.

An-Other Perspective

How are disabling discourses communicated and how do people with disabilities understand and respond to disabling discourses? This theme emerged as an issue during the follow-up interviews. The participants' understanding of the discursive construction of disability in non-disabled consciousness is revealed in a variety of ways throughout this study. Issues, such as changes to building codes, the lack of information on sex, and the problems associated with negotiating care needs, describe the ways in which these discourses work to produce constructions of the disabled subject. Participants' analyses of these issues inevitably return to the attitudes of non-disabled people. Kelly's example below, of changes to building codes and how this relates to non-disabled people's misconceptions about the lives of people with disabilities, highlights this theme:

Kelly: You can reinforce Acts, like the Discrimination Act, to make it illegal. But you cannot change people's attitudes and it's people's attitudes that count. Especially in employment situations. Anyway, standard practice codes still don't meet the requirements of the average disabled person. Have you checked out the toilets? They are so small the disabled toilets often. The ones in the City Health for example, and that's a brand new blimming building. They just assume that all the wheelchairs are exactly the same size. Um, yeah and its all very well having the Discrimination Act but what's the point if you can't get in the damn building in the first place. Your automatically discriminated [against] aren't you!

Margaret: I think people are always going to have an attitude, always. I think it can be changed to a point, if people don't want to change, they're not going to change. That's just everyday life and there are people out there who are prepared to change but, [sigh]. People's attitudes are always going to be different. I mean, I know people out

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there who think that those of us who have physical disabilities, or mental disabilities shouldn't be out there in the big wide world.

The claims of people with disabilities are not going unheeded. People with disabilities have articulated their claims and changes have been made. However, the participants suggest that in order for the experiences of people with disabilities to change, a re-orientation of non-disabled people's attitudes is required.

Henrietta suggests that there is a need to resist complacency; changes that seem to benefit people with disabilities should not be accepted uncritically. French (1994) would support Henrietta's suggestion. Comparing her own experiences of discrimination in 1967 unfavourably with her experiences in the 1990's, French asserts that it is important to resist the empty and dishonest rhetoric of equality. The participants suggest that disability friendly policies and practices evoke a variety of responses, from open hostility to unspoken resentment:

Henrietta: I think disabled people get lulled into this false sense of security that non-disabled people don't mind building ramps, or you know, car parks and all the rest of it. But I've found that there's a lot of resentment towards those sorts of things. And some of it... it can have a negative backlash to people with disabilities. I remember a woman called Mary was saying to me that she was trying to find a car park and um, she had her mobility card on her front windscreen and somebody trotted up to her and said, 'there's car parks for people like you over there'. You know, like, instead of saying that there's the provision there that non-disabled people should not park in those mobility car park areas, right. So that if all other car parks are full there's at least those ones allocated for people with disabilities. But this was turned around to say you've been rationed to ten car parks between all of you sort of thing, and that's where you park. So it's all turned around.

Using this example to stimulate discussion on this point at a later date elicited the following remarks from Jane:

Michelle: [...] I mean you should have places enough any way.

Jane: Because you can't walk the distance you can't wheel the distance.

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Michelle: *And getting around takes longer...*

Jane: *Yeah... So um.. there's some very sceptical people out there. Unfortunately they don't sort of work the issues through before they start shooting off about it.*

Jane suggests that non-disabled people do not consider such issues. The fact that car parks for people with disabilities are there to mediate the material realities of having a disability is not a part of their consciousness:

Henrietta: *We don't set up car parks just for ourselves just for the fun of it. They're there because if you drive your own vehicle you need that extra wide width just to get your wheelchair out of the car for goodness sake.*

Popular feminist non-fiction written at the beginning of this decade suggested that the women's movement had made significant changes in the lives of women, but that these changes should not be accepted complacently (Wolf, 1990, Faludi, 1991, French, 1992). These authors identified a backlash against the positive changes that can be seen in the lives of women. Jane, Henrietta, and Mary's, stories and analyses suggest a need to be alert to the negative consequences of the new found freedoms or positive changes experienced by people with disabilities. It can be argued that if changes that mediate the physical manifestations of having a disability inspire negative backlashes against people with disabilities, then the politics of claiming identity needs to be approached from a range of different perspectives. In the following section the tensions between claiming and dis-claiming disabled identities are discussed.

Fashioning, Claiming and Resisting Identities

Fashioning Identities

The theory that identities are 'fashioned' rather than imposed or arbitrarily chosen is forwarded in this analysis. The idea that people with disabilities are people first and that a disability should not be regarded as the major feature defining their lives is gaining acceptance in non-disabled society. This allows people with disabilities more scope for the fashioning of identities outside of disability. Identity is never a matter of choosing an identity and fashioning ourselves to fit that particular identity. Although, we may have choices to craft identities and present ourselves in certain ways, (Kondo, 1990) the choices for people with disabilities may be more limited.

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The participants' opinions about the fashioning of identities are characterised by personal contradiction. The quotes below suggest that, on one hand, disability 'just is', there is no choice in claiming or not claiming an identity. While, on the other hand, it is also suggested that disability is not always the starting point for forming an identity, and if it is a starting point, it is not one to which the participants often returned.

Kelly: [...M]y disability affects so much of my life. It's a part of me. So yes, it defines me, but it defines me in a different way. Instead of being disabled I see myself as a person with a disability. Whether it be... This is what I say to people, 'I'm female, I'm a student, I have a disability, I'm doing a degree, I'm a producer, director, script writer, I've been on a student exchange. So I could talk about things, subjects some of them I could talk about on their own, but because my disability is a part of me, it affects everything I do, so you can't just pick out one part. But I'm always making jokes about it, that concern how if people have to accept me they have to accept my disability.

Margaret: [...M]y disability sticks out, so I think that.. um.. a lot of people think of me now, now that I've grown up as Margaret, rather than Margaret with a disability. [...]. I think that people are [be]coming a bit more aware that you can't put that label on [people with disabilities] yourself if you don't really know them.

Jane: I've never really dwelt on the fact that I have a disability, probably mainly because of the way I've grown up with an attitude towards my own disability. I don't think of myself as having a disability. Um, and, I guess because I don't see myself as having a disability I come across to people who immediately treat me as a person and then something might happen in which I might be limited, and both of us realise immediately that we have a... I have a disability. [...] I don't think I've ever let my disability be an issue and I've been lucky in the way I did grow up that my disability has not been the issue to me that it has been to a lot of other people.[...]

There is evidence of contradiction and ambiguity in the participants' discussions of their experiences of having a disability. The method was designed to allow contradiction and multiple stories to evolve from the research. This is an aspect

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of the postmodern practice of paying attention to multiplicity and diversity. Kondo (1990:45) suggests that:

*it is important to realize that conflicts, ambiguities, and multiplicities in interpretation, are not simply associated with different positionings in society - though of course this is a critically important factor - but exist **within** a 'single' self (emphasis in original).*

The participants who experienced disability from an early age spoke of their lives in different ways from the participants who have acquired disability in later life. Jane offers an insightful analysis of how people who acquire disabilities in later life negotiate their disabilities:

Jane: [People who acquire disabilities in later life] are very engrossed in an able-bodied world and unless there is something that is affecting them directly, you never hear sight, nor sound, nor hair, of them. Then suddenly, when there is a real issue on, they'll turn up to an organisation like DPA [Disabled Persons Assembly] in order to get a bit of muscle behind. [...] Unfortunately those of us who have been born with disability, or had it since a very young age, will see these people as not being at all helpful and bettering the lives of people with disabilities and yet those people, if they wanted to, could do a lot to help change the, you know, the whole disability structure because there are some very very astute people out there, who go on to be lawyers and what have you.

The stories and the views of the participants suggest that if you have a congenital disability or have had a disability from early childhood, the issues around the political expedience of claiming disabled identities are different. The politics of claiming identity developed as a theme in its own right.

Claiming Identity

Participants had very clear, concise and well formed views as to the issue of whether it was politically expedient to pursue a politics of identity. The participants' analyses suggest that, while claiming identity brings with it a degree of marginalisation, it also provides the political basis with which to challenge experiences of marginalisation:

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Henrietta: [...] *If we say we get into that identity politics bit. If we say we are gay men, etc, etc, then you're leaving yourself exposed to being more marginalised. So then if we don't ever take on that identity as a group. We're gay but we don't have to wear it on our selves type thing [...] they are rejecting that sense of identity or structure of support to access what's happening for them.*

The research suggests that rejecting this sense of identity or structure is not supported.

Kelly: *People with disabilities have to learn to say what they want... have to stand up for what they want, so that they can get their needs met because otherwise...*

Morag: *So what you do Michelle, [is] you get erudite and um, positive people who just happen to have a disability and put them in a position in the process.... [...] But it has to be at the grass roots. But it has to be on merit.*

Kelly speaks of *learning* to say what you want, while Morag suggests using *erudite* and *positive* people in order to make claims. Kelly and Morag both suggest that making claims, or asking for what you want is not a simple process. hooks (1989) writes of the problems involved in voicing challenging claims. She suggests that it is important, for the people who stand in solidarity with people who are oppressed or exploited, to understand that finding a voice is a necessary starting place for liberatory struggles. This study suggests that while identity politics may no longer be appropriate for academic feminism, it may continue to be a useful starting point for women with disabilities.

Resisting Identity

As discussed in chapter one, feminist rejection of identity was grounded in situations in which the hegemony of politically correct identities took precedence over political objectives (Guy, Jones, & Simpkin, 1990). The strategies suggested above, such as appointing people on merit and standing up for one's own needs, are not the simple reductionist deployments of identity argued against in feminist politics. A disabled identity is conceptualised as a useful starting point. A politics of identity is not accepted unquestioningly or unconditionally. Identity politics is accepted as a politically strategic ploy but not as a limitation of lifestyle or lifestyle choices:

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Margaret: *Oh yeah. There's only so much that you can learn with your own identity, you know, identity groups.*

Morag: *I think, to nip back a bit, you are supposed to only mix with people of your own kind, as in other crips or other people who have disabilities. That's not necessarily true.*

Identity issues are approached from a number of different perspectives in this thesis. Identity politics have been used to achieve political goals in New Zealand's recent history. In this study, the participants drew upon the experiences of other groups who have used shared identity as a basis for emancipatory claims. Boyles (1993) also links the experiences of Maori people and the experiences of people with disabilities, suggesting that these insights can be employed in the production of new emancipatory research methods. Gay, lesbian and Maori rights issues have been used as examples by the participants. The marginalisation of people with disabilities was equated to racist practices. Participants asserted that equivalent behaviour towards Maori would not be tolerated and the question of why people with disabilities should have to put up with public displays of disableism, when public displays of racism are not tolerated was raised:

Morag: *To put it in a different way... a parody. You imagine if you went to a group of Maori people, you will live la la la, and you will do la la la, the shit would hit the fan. Do you get my drift?*

The discussion above presents identity politics as a site at which complex and contradictory issues are raised. It cannot be denied that identity politics can achieve positive goals. Identity clearly has a place in struggles to change marginalising practices and disableist discourses.

In Chapter One of this thesis the question of whether it is politically expedient to make claims on the basis of identity is discussed within the context of the feminist essentialism/anti-essentialism debates. The essentialism/anti-essentialism debates foreground the problem of making claims on the basis of shared identity. The conclusion reached in this chapter is that whether or not there is something essential about being a woman, or having a disability, identities have meanings attached to them and these meanings can be used strategically to achieve politically desirable goals.

None of the participants would deny that having a disability has a very real impact upon their lives. Nevertheless, the participants' responses to questions about the politics of identity could be located on both sides of the essentialism/anti-essentialism divide. This in itself could be regarded as a site at which productive dialogues might be pursued (see Schor, 1989). A politics of identity can be both a source of shared strength and a catalyst for further oppressions. The challenge is to determine how best to utilise identities to achieve emancipatory ends for people with disabilities in this particular moment in time. The following conclusion draws together the analyses presented in this chapter, and continues the process of making connections between the research and the theoretical concerns raised in Chapter One.

Conclusion: Moving Beyond Simple Deployments of Identity

The identification of people with disabilities as a significant group has led to changes, such as positive employment practices and changes to building regulations, to name two examples. The politics of identity around these issues are complex. On one hand, these policies are welcomed as they have made significant changes in the lives of women with disabilities. On the other hand, disquiet is expressed on a number of levels. For example, disability friendly changes to buildings improve quality of life for many people in the community, not just people with disabilities. Yet positive outcomes such as these are rarely acknowledged. If the wider benefits of such changes were acknowledged then people with disabilities might not be subject to the practices of marginalisation which result from the perception that they receive special treatment.

A variety of ableist discourses may underpin comments, such as, '*there's car parks for people like you over there*' (in *Henrietta's account above*). However, regardless of the specific ways in which such comments are discursively constructed, they convey the message that having the identity of a person with a disability is inferior to having a non-disabled identity. This brings sharply into focus, the question of whether a politics based on identity is politically expedient? Postmodern feminist interrogations of identity politics would suggest that it is not, however the participants' stories and analyses would suggest that it is.

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In Chapter One it was argued that the usefulness of identity politics as a political tool, is directly proportional to the degree of marginalisation to which a particular group of people is subject (see Fuss, 1989). Utilising a Foucauldian analysis, Weeks (1985) examines the issue of the usefulness of identity as a political tool. Weeks suggests that, once the norm has been challenged the need for the original identity groups, upon which the basis of these challenges were formed diminishes as they have lost some of their relevance in the success of the challenge. Speaking of the challenge made by homosexuals, where these identities became the starting point for challenging social norms, he asserts that:

...through beginning with the categories as they existed, the activities of the new movements gradually evacuated them of any meaning. For the elaborate taxonomies and distinctions existed in the end only to explain the variations in relationship to the assumed norm. Once the norm itself was challenged, then the category of the perverse became redundant... (1985:244).

Until such a stage is reached, however, identity remains an important political construct. Sawicki (1991) talks of the need to understand our various identities in the initial stages of political challenges in order to make our challenges stronger. As suggested in Chapter One, identity can not be simply discarded on the basis of inherent essentialism.

Where does disability politics sit in relation to Weeks' political perspective? How do we determine the degree of marginalisation to which people with disabilities are subject? The participants' stories suggest that marginalisation is a situationally specific phenomena. The choice to embrace or reject identity politics is not a simple one. There may be (as Margaret suggests above) only so much you can achieve on the basis of identity, however, the research also suggests that the potential strength inherent in identity based politics is important for women with disabilities at this particular moment in time.

The participants' views on the subject of identity give some indication of how the theoretical analysis offered above might be utilised. This study aims to produce intersections between feminism and disability, through a participatory research method. The participants' stories suggest that distinctions between non-disabledness and disabledness continue to define the lives of women with disabilities. One of the participant's views on her effective exclusion from a feminist group reinforces this conclusion:

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Henrietta feels disillusioned with feminist groups. Women's groups don't offer much support for women with disabilities. They argue that it is not their role to look after women with disabilities as this reinforces women's caring role. Henrietta sees people with disabilities as 'a tool of oppression rather than the oppressors.' The reluctance of women's groups to take on any part of the caring role usually makes women with disabilities reliant on the help of other women. Either unpaid relatives in the home or paid caregivers. So the reluctance of women's groups to care for women with disabilities doesn't really challenge anything as far as women doing the caring is concerned. 'Women's groups talk about supporting women but they are very selective about what groups of women they are prepared to support' (excerpt from Henrietta's Life History).

Matthews supports Henrietta's assertion stating that, '...disabled women have largely been ignored by feminism...' (Matthews and Thompson, 1993:134). Hume (1990) also suggests that the women's movement has neglected women with disabilities. However, disability politics may not be a safer place for women with disabilities to direct their energies. As long as 'man' continues to be the privileged signifier and 'woman' is defined in opposition to this, there is no reason to assume that disability politics will address the needs of women. Oliver (1990:71) suggests that, 'like many social change movements, the disability movement has often directed its energies towards primarily male experiences'. The experiences of women with disabilities in Aotearoa/New Zealand support Oliver's observations. Wicks (1991) suggests a need to theorise the interaction between sexism and ableism, and Georgeson and Savage (1989) suggest that the DPA needs to make a commitment to support women with disabilities.

It is necessary to critique the inadequacies of feminism and disability politics in order to find ways to better theorise, understand, and politicise the marginalisations to which women with disabilities are subject. Despite feminism's historical ignorance of disability issues Matthews (in Matthews and Thompson, 1993:134) found that her enrolment in a Women's Studies program provided her '...with a platform to address and share my own knowledge and experience of disability...'. This questioning of the place of identity in emancipatory politics raises power issues. The issues of who can speak and

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what can be spoken are potential bases from which the political potential of politics based on a notion of shared identity can be measured.

Forming coalitions between groups with similar political objectives (Sawicki, 1991) may be one way in which alliances between feminism and disability can be forged. However, coalition politics cannot be embraced uncritically. Addressing the issue of differing identity through a discussion of the relationship between being non-disabled and researching into disability issues, Appleby (1993) suggests that the notion that we can be on each others side is not as emancipatory as it might seem. Appleby foregrounds the fact that some identities are socially more powerful than others. Appleby's critique does not suggest a return us to the concept of hierarchies of oppression³ - where the identities of those most marginalised within mainstream society are privileged. Rather she suggests that a recognition of difference and diversity would allow alliances to be forged between women with differing and fragmented identities, where diversity would be acknowledged as a positive strategy against the many forms of oppression in women's lives.

Despite the shortcomings of identity as a political strategy, it seems that in the short term at least, identity remains a useful and viable political construct. Postmodernism is characterised by increased attention to multiplicity and diversity. Identity itself has become an ephemeral and complex issue. An analysis of the discursive construction of disability and the possibilities of emancipatory projects in relation to the body (Chapter 6) and, the self (Chapter 7) continues in the following chapters.

³ The concept of hierarchies of oppression is discussed and critiqued in Chapter One.

Chapter Six

Poked and Prodded, Tested and Tried: The Body On Display

The Body

The practice of writing the body back into theory and research is particularly important in this study, as women with physical disabilities are often assigned subject positions on the basis of their embodied subjectivity as people with disabilities and/or as women. To be assigned either or both of these subject positions is to be marginalised within the context of a society in which non-disabledness and masculinity are hegemonic. In their book 'Deviant Bodies', Terry and Urla (1995:4) critique this 'modern fiction of Man' subjecting it to:

critical scrutiny by revealing that its sacred Oneness is based upon its distinction from a host of Others. Our strategy, then, is to deconstruct a particular bodily fiction that has been deployed for the maintenance of Man: the idea that individuals who deviate from that ideal are morally and socially inferior, and that their moral or social disruptiveness is always somehow embodied.

Analyses such as Terry and Urla's reveal the cultural underpinnings of relations of power and powerlessness within society. We can legitimately question why the upright figure of a man should be automatically invested with authority. Such an analysis disrupts non-disabled male hegemony and reveals sites at which potential resistances exist.

In Foucault's analyses, power and resistance are understood as co-existent: 'Where there is power, there is resistance...' (Foucault, 1978:95). Following a Foucauldian analysis, power is considered to be productive rather than coercive or repressive. Power 'produces reality - it produces domains of objects and rituals of truth' (Foucault, 1995:194). Power is considered to work in a capillary manner as working from the bottom up, rather than the top down. Foucault conceptualises power as being everywhere because it comes from everywhere¹. The body in relation to this analysis can be regarded as a signifier of anatomical forces and an embodiment of power. Power works through and on the body.

An analysis of the body has developed as a major theoretical and substantive theme in this thesis. In the social sciences, theories of the body are a relatively

¹ See Foucault's (1978) discussion of the workings of power in The History of Sexuality, Volume 1.

recent development. Historically, social science like other academic disciplines, operated under the assumption of a mind/body split. Postmodern theory, and particularly feminist postmodern theory, challenges the assumptions on which this theory of a mind/body split rests. In its place the embodied subject located in a mind - body dynamic is proposed. Thus practices of 'writing the body back in' become both a site of resistance to and a means of moving beyond fictions of disembodied neutrality.

The importance of theories that write the body back in can be seen in relation to the experiences of the research participants. Writing the body back into theory provides the space for an analysis of power relations at the site of the body. One of the most thought provoking aspects of this chapter is the link between lack of privacy and power issues. It is interesting that the participants' overt analyses of the ways in which power operates in their lives often takes place at the site of the body. The inappropriateness of non-disabled people's actions and policies is a recurring theme, as is the issue of non-disabled people's misplaced value judgements and the gap between the reality of disability and non-disabled perceptions. A case in point is privacy. 'Privacy' is a concept that has very different meanings for non-disabled and people with disabilities. Privacy is something that non-disabled people tend to take for granted. But for people with disabilities the right to privacy is not clear cut or easy to establish. Privacy is a particularly precious commodity for people who require carers.

This link between privacy and power issues is vividly illustrated in the participants' discussions of caring agencies. Themes concerning privacy and sexuality, and privacy in terms of negotiating relationships with carers themselves, also developed as a significant theme. The scrutiny to which the lives of women with disabilities are subjected is played out at the site of 'the body'. This analysis also addresses power issues in relation to more general relationships between people with disabilities and non-disabled people.

The themes in this section are related to the participants' opinions of non-disabled people. The assumptions people make in their everyday interactions with people with disabilities can be regarded as an aspect of 'relationships of power' (Foucault, 1988b:12). Kerr (1996) suggests that an understanding of how relationships are produced and maintained is crucial if we are to affect change in the lives and choices of people who are seen to be different. The following themes developed from the participants' discussions of: non-disabled people's

assumptions about what it means to have a disability; non-disabled people's responses to women with disabilities and issues around privacy and sexuality.

Non-Disabled People's Assumptions About Disabilities

Relationships, Non-disabled People's Expectations, and Public Scrutiny

Non-disabled people in relationships with people with disabilities are assigned certain subject positions by the rest of non-disabled society. Morris (1991:141) writes of non-disabled peoples' failure to recognise that most relationships where a person with a disability is '...receiving economic and/or personal support from a non-disabled person are reciprocal relationships in which the disabled person is giving as well as taking'. At their most extreme, a type of moral superiority, or holy status, is attributed to non-disabled people in such relationships. The participants challenged the imposition of these restrictive and unrealistic subject positions throughout the interviews. The idea that a non-disabled person in a relationship with a person with a disability must be a saint was cited as particularly hurtful. Such popular misconceptions deny the role of the person with the disability as partner, mother, or friend. Discourses of masculinity and femininity also affect such relationships. Stacey's description of other people's perceptions of the relationship between herself and her twelve year old son, and the ways in which this contrasts with the realities of the situation, captures the essence of this situation with regard to mothering:

Stacey: [...] I guess I get that a lot of the time with David my son. OK, he's a good little kid a lot of the time but he can be a right little backside too. [...] But people straight away, they say, 'he's mar-r-r-velous'. He doesn't do this, that, and the bloody next half the time at all... In fact he abuses power. Oh hell, he's terrible at times. Other times he is, he's good. Um, but he goes through hassles too I suppose eh. It's always looked upon that they must be Saints. It doesn't make you feel that bloody good either if you've got the disability...

The participants' comments highlight the ways in which popular discourses of femininity and masculinity work to produce different options for men with disabilities to those available to women with disabilities. A non-disabled man in a relationship with a woman with a disability is likely to be heralded as a saint.

While a relationship between a non-disabled woman and a man with a disability is likely to be questioned:

Henrietta: *I think it's much more difficult [for women with disabilities than for men] to find partners. I think, probably, when I look at it now the socialisation bit. I think it's also about how people react to a guy who's providing care... particularly to a woman. Um, a lot of people that they meet, both men and women... um, I don't know... build them up to be holier than thou...*

Jane: *[...] And also the other thing that comes into it is you look at the male as being the so called bread winner of the household... So, oh, the poor woman, she's going to have to go out to work, look after him and if they have kids, bring up the kids and all this sort of thing and it's just... You know... they've just laid their judgements according to what they think and see and, you know... for many it's not like that.*

Gender also relates to the process of resource allocation. It was suggested that a man with a disability gains easier access to a car and other material resources:

Jane: *[...] I have done things that, in my life time that, I think that a man with a disability has it easier than a woman. I've seen it happen time and time again. Um, I guess because he's a man he seems to at times be able to access things easier, especially if it's a woman who's doing the assessment.. The male kind of thing. You know, 'the male' kind of carry on. I guess it bugs me but, and we've all said; a lot of us will say that men with disabilities do have it easier. [...] It's crazy.*

Most of the participants had strong feelings about gender issues. Most of these could be classed as feminist. For example, Henrietta commented in her Life History interview that:

Societal attitudes are responsible for the fact that women and men have different experiences of disability.

Morag also stated that she is:

[...] no longer prepared to sit on the back bench and watch women and women with disabilities being sideswiped and put on the back burner.

However, not all the participants were sympathetic to such a gender analysis:

Margaret: *[...] I can tell you now I'm definitely not a feminist.*

The emphasis on a feminist interpretation of events was persistently resisted by Margaret. For Margaret, differences in disability take precedence over gender differences:

Michelle: *Do you think the problem for women with disabilities is different to the situation of men...? Educational opportunities and relationships are more acceptable for men?*

Margaret: *I don't think you should actually single people out like that... there's heaps of disabilities out there and I mean... Ok, I think that men are... are a lot more, and I think of my friends... I think men have a lot more opportunities as far as the work force goes out there in the big wide world, but at the same time, it um, now that things are coming together for women, we're still getting singled out.*

Michelle: *How do you mean getting singled out?*

Margaret: *Well I mean, there'll always be that thing like men are better at other things than women are, and that may be so or may not be so but, like, you find that a lot of men who have disabilities are into sport more than women.*

The participants' accounts portray a sense of lives lived on display. The section below centres on examples of how particular assumptions about disability translate into responses towards people with disabilities.

Non-disabled People's Responses to Disabilities

When faced with a new situation what we see, and what we hear, provide us with information. This information is generally processed on the basis of what we already know. Non-disabled people's initial responses to people with disabilities are often linked to bodily manifestations of disability. It can be

argued that such reactions result from a lack of knowledge of people with disabilities:

Henrietta: I guess that depends on the kind of disability you have, to a certain extent. If someone has a disability with communication, you know difficulties with speech, then the expectations of what... what people expect they're able to do is immediately lowered. [...] I've noticed with a lot of people... like with cerebral palsy, where their speech is affected, people just don't expect that they've got anything to say on a particular - on any topic at all.

Non-disabled people's attitudes to wheelchairs can be similarly unproductive. The sentiment that someone is tragically confined to a wheelchair is familiar in non-disabled discourse. While the reality of a wheelchair for a person with a disability is often the reverse. For people who need wheelchairs, the wheelchairs are tools that improve daily productivity. The following excerpt from Morag's Life History inspired the majority of the comments recorded below:

Tiredness motivated Morag to try using a wheelchair. She used the chair for some time but gave it up, because she found she was losing what mobility she had left. She now uses the chair strategically so as to get the maximum out of her days.

All the participants in this study have at some time in their lives used wheelchairs to their advantage. Despite this, ambivalence characterises the participants' attitudes towards their wheelchairs. This ambivalence can be located at the intersection between non-disabled discourses, captured in expressions such as 'confined to a wheelchair', and the everyday material benefits of having the right wheelchair:

Stacey: [...] I don't feel comfortable with the wheelchair anyway. When I say I don't feel comfortable, it's mental attitude to it, you know... [Later in the same paragraph] I could see the difference in me it was just incredible. Now in this chair I could almost get tea ready. In fact, I did one night.

Jane: Yeah, you know, and there again, it's not so bad now, but wheelchairs are looked on with a real stigma. I mean, I can remember when I was young at times being forced to walk, when I was just

literally so tired and exhausted and had literally no strength left in my body that I thought I was going to drop. Yet in my wheelchair I doubled what I could do in a day if not trebled because the energy that I was using in trying to get myself around. I mean what for goodness sake is so wrong with a wheelchair . [...] There's no stigma; no more than when people might choose to ride around in a car or on a bike. It's crazy, mad. They've got no idea. Ha, Ha Ha....

These examples highlight obvious and tangible aspects of non-disabled people's responses to people with disabilities and their needs. The processes by which people with disabilities are marginalised also occur at more subtle and insidious - but no less important - levels. Abberley (1987:14) suggests that the body is a site of oppression for people with disabilities, 'both in form and in what is done with it'. In her Life History, Margaret indicated that it is better for her health if her legs are elevated. Despite this, in public, she prefers her legs to be down on the foot rests of her chair as it makes her feel less conspicuous. Margaret described this issue as a sort of a toss up between practicality and vanity. Abberley (1987) would analyse this movement to 'normalise' the physical manifestations of disability in terms of the tension between the assumption of disability as primary and total identity and the simultaneous denial of the value of such an identity:

Margaret: Yeah everybody wants to look good and I honestly do hate my legs up, as I said it's not practical to have them down.

Normalising discourses affect the lives of people with disabilities in a variety of ways. Foucault (1995:304) suggests that the judges of normalcy are everywhere, 'the carceral texture [or disciplining nature] of society assumes both the real capture of the body and its perpetual observation...'. Non-disabled peoples' expectations of people with disabilities are part of the process by which such normalising discourses are communicated and solidified. The discussion of Othering above, examines the ways in which these discourses function in relation to wheelchairs. Further examples of the functioning of normalising discourses appear in this study. A perceptual gap between the reality of people with disabilities and non-disabled peoples' ideas about disability was discussed by the participants.

Discourses on disability function in such a way that non-disabled people consistently react to the easily observable manifestations of disability when the

main aspects of having a disability may be hidden. Basket weaving², infantilising and shouting at people in wheelchairs and the difficulties of finding a doctor with some awareness of disability issues emerged as some of the most extreme examples of the functions of normalising discourses about disability.

Attitudes are indicators of popular discourse. Critiques of the practices of marginalisation to which people with disabilities are subject, often returned to the attitudes of non-disabled people. Positive changes to public policy and better provision for people with disabilities generally, were spoken of by the participants. However, these changes were often regarded as a kind of lip service or as people being seen to do the right thing. French (1994:155) supports this suggestion stating that, 'there is a lot of pressure on employers to be seen to be "doing something" but the "solutions" adopted often take no account of the individual needs of disabled people'. The opinion that genuine change is contingent upon adjustments in non-disabled people's attitudes was a strongly articulated component of this study.

Attitudes have a very significant influence on the lives of the participants in this study. Margaret spoke of the attitude that people '*...who have physical disabilities or mental disabilities shouldn't be out there in the big wide world*'. Henrietta also spoke of things being '*leaked out into the big wide world*'. At many points throughout the construction of this thesis, a split was spoken of between the lives of people with disabilities and the big wide non-disabled world. Discourses of marginalisation are communicated to people with disabilities in very tangible ways. Normalising discourses, those that disseminate and maintain the status quo are pervasive. French (1994) illustrates this in her analysis of the gap between the empty promises of equal employment rhetoric, and the realities of her own experiences. People with disabilities are told what place they should occupy in the world even if the words are never spoken directly.

² This basket weaving caricature of career expectations for women with disabilities has been used as an example of a particularly irksome urban myth by both Henrietta and Kelly. Henrietta tells a story of visits to an extremely obtrusive school guidance counsellor. Every week Henrietta would go down with a list of careers she thought she might like to try. The next week the guidance counsellor would come back with a list of ten reasons why Henrietta could not do any of the things she wanted to do. His final recommendation, a career in basket weaving is something Henrietta feels she does not really have a talent for.

The Gap Between Reality and Perception

The ways in which normalising discourses, such as attitudes to wheelchairs, and the bodily manifestations of disability, such as speech, are conceptualised in the non-disabled world is just one aspect of the gap between the reality of the lives of people with disabilities and the preconceptions non-disabled people have about their lives. Although many of the disabling discourses analysed in this study are located at the site of the body, it is not the body itself that is the cause of these negative discourses. Attitudes and expectations for example, are merely indicators of popular discourses. The origins of these negative ideas about disability can be attributed to a wide variety of normalising discourses. Mirzoeff's (1995) analysis of the privileged position the deaf were accorded in the harem, is illustrative of the possibilities positive discourse of disability might be productive of. Negative expectations and attitudes can be located within a particular and culturally specific context. A critical examination of the things we consider to be natural might reveal that they are more fragile than we understand them to be (Foucault, 1980).

Information collected in the Life Histories suggested that non-disabled people's low expectations of people with disabilities was a major problem. Stacey's experiences of physiotherapy were presented to the participants in order to stimulate discussion:

'...but MS is always difficult; it's always different. I walked up the stairs and back down again, it took a long time but I did it. The physio yelled at me to get down off the stairs and back in my chair. I liked the pool... When I first went to the pool I had a tyre... The physio would flip her lid if I got out of the tyre. I had to get out of the tyre when she wasn't looking'. The physiotherapist seemed to think Stacey was going to 'drown or something'. In the end Stacey was swimming lengths. 'Twenty minutes is the longest you are allowed in the pool, its not always long enough...'

However, the follow-up interviews also revealed a different perspective on the question of non-disabled people's expectations. Non-disabled people's low expectations of people with disabilities were regarded as a problem, however, problems associated with overly high expectations were also emphasised. Kelly's responses to non-disabled people's low expectations are presented below:

Kelly: I think people's expectations, I could go into this forever, people's expectations, especially elderly people and middle aged people when they see people in a wheelchair they automatically think that you're dumb, deaf, and stupid. And Um, and they yell twice as loud or speak to the person [with you] and ignore [you]. And the person [with the person with the disability] might say, 'ask her, I'm not a bloody mind reader you know'. But some people just don't get the message and of course I'm probably an exception to the rule. A lot of people wouldn't expect a person with a disability to be doing a double major degree, for example. People perceive people with disabilities to be sitting on their butt doing crocheting and weaving baskets.

Or people would expect them to be locked away in hospitals getting 'the best care that they can'. People say, 'there are places for these people', I mean, get a life. (exasperated tone) [...] People at Church used to come up to me and rub my hand and say, 'would you like a bickie... I thought, oh Fuck'.

However, the problem of non-disabled people expecting too much of people with disabilities was a much more popular topic in the follow-up interviews. Participants had strong views on issues to do with expectations. Jane's response to Stacey's experiences and the problem of non-disabled people's expectations, captures the essence of these discussions.

Jane: [...] I know how cruel that is for somebody to assume that even though you've got a disability you're capable of doing this and you're not. [...] Now for me over the years I've learnt to tell them to back off and if I say I can't do it, then I know I can't do it and I mean I can't do it. That's all there is to it. [...] I guess to me it's never been an issue as to whether I can or can't. If I can't I can't. If I can, I can and that's it. If they ask me to do something and I can't I just say, 'don't be so bloody stupid, when do you think I'm going to do that?'

Non-disabled people's expectations - whether too great or too small - impact negatively upon the lives of people with disabilities. The examples above suggest that non-disabled people lack understanding of both the issues that are important to people with disabilities, and the realities of their everyday lives,

and so contribute to the problems having a disability engenders. The participants' comments in the following paragraphs, on the role doctors play in their lives, can be regarded as illustrative of issues that are experienced by people with disabilities in the wider non-disabled community.

Non-disabled Doctors' Responses to Disability

Keeping ourselves healthy can involve going to the doctor, finding out what might be wrong with us and establishing a way to manage it. This process is more complicated for people with disabilities. This study suggests that some doctors' responses to disability are firmly entrenched within non-disabled normalising discourses, and that as a consequence these doctors' have limited knowledge of the specificities of most disabilities. The main problems identified in this study were lack of medical knowledge and inadequate provision for material needs. Henrietta offers some insights about doctors and medical knowledge:

Henrietta: [...A] lot of it is pure assumption and speculation on their part. [...T]his is where it becomes very misleading to put disability under health, or medical health. Because doctors do have a very poor knowledge of issues relating to disability and the needs, the physiological needs... Because a lot of people with disabilities their [...] medical conditions are actually very complex. Often very rare conditions[...] Very few doctors have researched in the area; the sort of medical/physiological sort of stance about a particular condition.

The participants linked basic material aspects of having a disability, such as time often being at a premium and the physical layout of doctors' premises, to their impact upon people's medical experiences. Frustrating complications, such as being kept waiting for inordinate amounts of time, and being unable to manoeuvre in and through waiting rooms, can have an enormous effect on people's experience of going to the doctor. Munford (1990) analyses factors such as time and waiting as technologies of power. Keeping people waiting and not considering people in wheelchairs in the layout of waiting rooms communicates a lack of respect for and understanding of the needs and realities of people with disabilities.

Despite the difficulties involved in finding a good doctor, several of the women in this study have found and established good relationships with doctors. The services of these doctors are not taken for granted. Factors such as open mindedness about sexuality (illustrated by Kelly below) are an obvious example. However, more subtle factors such as a minimum of time spent in clinics and waiting rooms, accessibility and space for manoeuvrability, or finding a doctor with some awareness of disability issues were also cited as important:

Kelly: I've got a gynaecologist who's wonderful. He is open minded, you know, my disability is not a problem for him at all. And he, has, helped me in various ways and it hasn't become an issue for him. But I have come across doctors in the early days who said, 'oh no you can't do tha-at'. [...] You do get doctors who are quite narrow minded and I've had them before... When I was growing up and a teenager, I told my GP I wanted to have a baby and he said, 'Ohh... OK'. When I was growing up and I was younger, a lot of the doctors would treat me like an object rather than like a person. Of course we're talking like in the 70's and stuff but now times have changed so much. Attitudes are changing gradually but, some, most middle aged people are still stuck there... Times have changed, people are becoming more optimistic but it depends on the person. Like I said I managed to get someone who is really open minded and there aren't a lot of doctors like that, I guess I'm just fortunate.

Doctors' responses to people with disabilities (like non-disabled peoples generally) are often a response to bodily manifestations of disability, made on the basis of popular misconceptions that have little to do with the reality of a particular disability. Due to a variety of factors, all linked to ignorance of disability issues, non-disabled people's responses to disability are not viewed particularly positively by the participants in this study. Sullivan (1996) links such experiences to cultural inscriptions of the body, suggesting that such experiences stem from the presupposition that the inner self can be known from outer appearances. Historical contextualisations of the experiences of disability within non-disabled culture also contribute to the destabilisation of popular misconceptions about people with disabilities (Connors, 1985, Oliver, 1990, Sullivan, 1996). People with disabilities are inscribed by their bodies in multiple ways. For the participants in this study, non-disabled people's responses to this bodily inscription of disability was one of the most negative ways in which ableist assumptions manifested themselves.

Negotiating for Resources

Having a disability brings with it the need to negotiate complex bureaucratic structures. The problems and practices associated with this and the practices employed to address these problems are recurring themes in the Life Histories and the follow-up interviews. Henrietta and Kelly articulate an awareness of the need for skills in negotiating the system and an analysis of how and where these skills are gained:

Henrietta: People who were born within fairly affluent families [...] they've certainly had a few more advantages.[...] And they certainly see themselves as being educable. You know that education is going to be the way for them to be self reliant, um, etc, etc. [...] For some people from the working class background having to be assertive and articulate and being able to express your needs... [...people get] totally confused by the whole process and then doctors or professionals will tend to leave them out of their decision making. ... So there's that whole knowledge thing and level of being able to articulate themselves.

Kelly: Also some people who aren't like me will just sit there and wait and wait and wait and say nothing, and they know that people sit and sit and wait and say nothing, so they'll take advantage of that. They'll say he's not in desperate need for it, you can wait.

Issues to do with the material realities effected by ableist practices and possible methods of mediation are offered in the participants' analyses. Henrietta and Kelly provide analyses of the process of negotiating for material resources. They suggest developing the skills to negotiate a path through webs of misunderstanding, by encouraging people with disabilities to be more proactive in the process of getting their needs met as a possible strategy. For example, Henrietta suggested that people who need care, be trained to train their own carers.

Needing carers to perform everyday intimate tasks also raises a number of issues that require the use of mediation skills. Active management of issues to do with privacy and sexuality emerge as particularly important in the following section.

Privacy and Sexuality

When I first began this analysis of the follow-up interviews, privacy and sexuality were divided into two separate categories. It became more and more apparent, as the analysis progressed, that these two themes were intricately and intimately linked. For women who require full-time carers the link is obvious. Caring is an intimate task and carers have access to the most personal aspects of participants' lives. The participants who do not require full-time care described constraints on forming relationships, in terms of public scrutiny and non-disabled attitudes. Within the context of such disabling discourses, reluctance to form intimate relationships characterises participants' attitudes. Participants who did form relationships suggested that the assumed a-sexuality of women with disabilities, and subsequent lack of information available on sex and sexuality, limits their choices.

Choices related to forming intimate relationships are constrained by issues related to public knowledge of private issues. This can be linked to the idea of panopticism, or the means by which power works through techniques of surveillance (Foucault, 1995). Revealing private information is often either unavoidable or necessary. Intimate relationships can rarely be kept secret. As the quote from one of the Life History interviews below illustrates, this lack of choice makes privacy a sensitive issue:

'You have very little privacy'. There have been times in [the participant's] life when she has been interested in pursuing relationships with men, but the logistics of doing this have put her off. 'If you have a carer to put you to bed and get you up, you have very little privacy'. [The participant] sees her options very clearly. 'If you have relationships, you have to find a way to move around (caregiving needs) or you don't have a relationship at all... You have very little privacy from the people involved in your life, because the people are there all the time... The things I find personally very difficult is toileting... bathing, dressing... stripping off naked in front of other people. You have no privacy... After a time you shut off, but it's always there'.

Private knowledge of public matters is a familiar aspect of having a disability. A recent Australian report, written for the Office of the Privacy Commissioner,

suggests that people with disabilities not only feel that they are inhibited from forming sexual relationships, and from performing sexual activities by lack of physical, social, or emotional privacy, but they also find that information about their sexuality becomes part of public discussion or ‘accepted knowledge’ of them and their lives (Montague, 1993). People with disabilities are constantly asked to provide details of their lives for assessment purposes. As a consequence, keeping things that don’t come in for formal public scrutiny private, becomes important. Encouraging discretion and confidentiality in relationships is one way in which privacy is maintained. Factors that compromise privacy, such as carers gossiping about other people with disabilities, were only ever mentioned in a negative context in this study.

Making space for privacy requires intricate care and planning. Relationships with carers are particularly complex, as they are an everyday manifestation of the surveillance to which the lives of people with disabilities are subject. Establishing a professional relationship with carers is one way in which such power and knowledge issues are mediated. However, as the final section in this discussion of privacy and sexuality demonstrates, establishing professionalism is a complex process.

The ideas discussed in the introductory paragraphs above are divided into three categories below. In the first, the participants’ concerns about the ways in which assumptions of asexuality affect their own lives and the lives of other women with disabilities, are discussed. The second category is concerned with issues around sex, sexuality and intimacy. While the final category in this section, on privacy and sexuality, looks at power and knowledge and their relationship to one another.

The Assumed A-Sexuality of Women with Disabilities

Sex is a very popular topic. Manuals about how to have better sex are bountiful. Popular magazines feature articles about sex, and entire sections of bookshops may be devoted to sex and sexuality. Despite this plethora of sex related material, the participants suggest that finding literature about sex and sex expression specifically related to disability is a difficult task. Such literature is often about the mechanics of changes to the body as the result of disability. In addition, doctors and health professionals are regarded as a limited source of knowledge on issues to do with sexuality. A search with the aid of the Multiple Sclerosis Society in Wellington, provided some positive information about

sexuality for women with disabilities (Hume, 1990, Appleby, 1993, DeLoach, 1994, McAllan & Ditillo, 1994). However, there is a decided dearth of information concerned directly with sexual pleasure.

The lack of information about expressions of sexuality for women with disabilities can be regarded as a symptom of a wider problem identified by the participants in this study. That is, that the expectations non-disabled people have of people with disabilities are lagging behind the expectations people with disabilities have for themselves. Not waiting around for the non-disabled world to say its OK for you to have a sex life, women with disabilities are claiming the right to a sexual life:

Kelly: [...] In the olden days, a lot of people assumed that you couldn't have sex, so it's just, you know, once they know that people can, its... [...] In the olden days, sex for the disabled would be 'absolutely out of the question'.

Jane: But because I was living in an institution it was expected that I wasn't going to get married. Those sorts of questions were never asked. I mean I never got questioned on any of my sexual feelings or whether I craved for boyfriends, or anything like that. They never got asked of me, and I kind of just drifted through my teenage years with my so called normal girlfriends doing the things that they do anyway, regardless of whether the nuns knew or not, and it didn't become an issue. I think naive, probably, I wouldn't say that they were naive. I guess I was really lucky, when I look back now. I guess that they always trusted me. Whereas I did see a lot of the girls that grew up with me the nuns didn't trust. But I could get out and I had my freedom and they seemed to trust me.

Stacey: People think that you've lost it basically. This has come up in my life recently and know you don't lose it. [...] I've actually been speaking to somebody about getting some tapes I saw at a seminar one day.

Morag: 'I asked [the doctor at the rehabilitation unit], 'What about sex?' It's not considered nice for people with disabilities to think about these things. Good grief, what a disgrace! He was shocked.

Afterwards he came back and talked about it. But what he said wasn't useful' (excerpt from Morag's Life History).³

The impact of discourses of a-sexuality does not stop with prohibitory attitudes and restricted information. The assumption of a-sexuality also impacts in terms of negative perceptions of intimate relationships between a woman with a disability and a non-disabled person.

Sex/Sexuality/Intimacy

Non-disabled people's perceptions of the dynamics of a relationship between a woman with a disability and a non-disabled partner constrain the choices made by women with disabilities:

Michelle: I think you said that people don't think that ablebodied people might be lucky to have the person with the disability...

Henrietta: Yeah, they don't see what she can contribute[...] It's that whole dependency thing. 'Oh gee, he's so good, he's prepared to look after her'. And it's not recognising the reciprocity within the relationship, which happens in any relationship.

Uncertainty about the future, and knowledge or fear that a disability is going to worsen, affects how women with disabilities negotiate their relationships. There is an assumption that a non-disabled partner could not, or would not want to cope with higher levels of disablement:

Stacey: I have to admit that personally I'm too scared to be involved because of it (disability). I've got an attitude I think. You know Paul totally disagrees with me. Live for the day. [...] He used to try and get commitment out of me, and my theory of life I suppose at the time because I was so peeved because I was in a wheelchair, was just live for today. Enjoy it today, you know, and that was it. He found that really hard to cope with. [...] I didn't want to admit that what I was saying really was, 'God wouldn't I love to have a relationship but I can't'. I don't think I want to because I'd be holding him down. [...] But this is years down the track and he's still around so... But he

³ This excerpt was used in the Interview Guide for the follow-up interviews.

knows how I feel about it so he doesn't over-push it. As I said to him I'm really glad he's still there[...]

Jane: [...] And I don't think there are many of us who would go into a partnership. Whether it was one that was living together or getting married without really talking through the issues and saying, 'well from my point of view you realise my disability is going to worsen and as I get older you're going to have to do more and more and more for me'.

Speaking of uncertainty about the future, in the context of a conversation about the problems of maintaining a degree of privacy, Jane suggests that reluctance to enter a relationship is exacerbated when ageing and increasing levels of disability are added into the picture. In her article, 'Becoming an Older Disabled Person', MacFarlane (1994:255) talks of the 'enormous number of losses that have received no recognition'. MacFarlane's analysis covers similar issues to those addressed in this study. A huge deprivation in relationships, not having the opportunity to establish and maintain partnerships, being denied one's own sexuality and not having adequate support to enable the enjoyment of the experiences of partnership or children, are among the issues she raises.

The participants' accounts suggest that caring and disability are both devalued, and intimate relationships are routinely scrutinised. It is not surprising that caution characterises the participants descriptions of their responses to the question of relationships.

Power and Knowledge, Privacy and Confidentiality

In this study it is argued that disability is produced in relation to non-disabledness. This argument is linked to the postmodern understanding of bodies as produced within relations of power. Foucault's (1978) analysis of bio-power in which the body is conceptualised as an organism, manipulated to produce certain socially desirable outcomes, is of relevance in this analysis of the relationship between power and knowledge and privacy and sexuality. For people who require full time carers, the body is repeatedly and intimately on display. The ways in which the body is cared for and the respect given to issues of privacy and confidentiality, impact upon the discursive production of disability. Foucault would argue that power is working through the body in order to effect particular outcomes. Foucault (1995:209) writes of the way in which

power works through techniques of 'subtle coercion' under a schema of 'generalised surveillance'. In Foucault's work, sexuality emerges as a site at which power is localised. In the participants' stories and analyses, the idea that it is not acceptable for a woman with a disability to have a private sexual life is communicated via a variety of discursive practices.

People who require full time carers have little opportunity to have a private sexual life. From this perspective issues around privacy and sexuality are intimately linked. Relationships between carers and participants dominated discussions of these topics. The difficulties involved with developing a professional relationship within the context of a job that requires a high level of intimacy, were articulated strongly in this study. Discussions of the relationship between carers and the people receiving the care, revealed that these relationships are often viewed in abstract terms, to the degree that they are analysed in terms of power and knowledge. Jane's comment that 'there is a lot of trust being played between you and them' captures the core of this issue.

Trying to maintain a friendly relationship and simultaneously establish some privacy and distance (non-intimacy) from caregivers is a difficult task. Power is understood in this thesis in terms of relationships between human beings that are subject to constant change. 'These relationships of power are changeable relations, i.e. they can modify themselves they are not given one and for all... [Foucault suggests that these relations of power are] ... changeable, reversible and unstable' (Foucault, 1995:120). Kelly provides a nuanced description of relationships of power in the caring relationship:

Kelly: Yeah, so, and like, it's really again back to the privacy issue and security. It's really hard not to... you've got to strike a balance in the relation. You've got to maintain a balance between some kind of professional relationship, and have a routine. But it's really hard because when you're working on such an intimate level you want to become friends, but then you don't want to get too close because people will take advantage of you... You want to keep your flatmates out of it. Because if they get involved with fights between me and my carer. You know you just don't want to involve them in it and it's so easy to do that and you know they'll take advantage of that. Whether it's two years away or what. And then it's; I thought we were friends, you know. It's better to keep your personal life out of it, too. But then sometimes your personal life comes up in your conversation which is

always hard, because you know what girls are like... gossip, gossip, gossip.

An undertone of sensitivity and outrage prevailed throughout discussions on this topic:

Jane: So some of them used to come in and some of them would be really nosey, you know just asking questions so that I used to say for Gods sake don't be so bloody nosey. Mind your own business, and you know that annoys me, because I don't really see what right people have to keep on asking questions.

Analysing the information shared by the participants within a Foucauldian framework highlights power issues. Power can be seen to be working through discourses of disability to deny privacy in the lives of the participants in this study. However, resistance to such discursive constructions of disability are in evidence below in the participants' resistance to such practices. The participants establish their own set of guidelines for dealing with problems such as this. This analysis of power and resistance is developed further in the discussion of sexuality below:

Henrietta: [...] I've found it difficult, I have from time to time found caregivers reading mail. It's sort of nosey value. They'll pick it up and that sort of stuff so I've had to be a lot more careful because of that. And... what else... I guess the fact that you know... that thinking I trust a helper and having conversations with friends here and that sort of stuff and realising that some of it actually gets leaked out into the big wide world. And I have to make the point sometimes, when somebody has been there through the whole conversation, that it doesn't leave the house. You know, etc, etc. And I guess that is where I found it really stressful. Because, especially when I was going through those stressful times at work, I would often sound off to the caregiver and then found out that some of that was going back out. We've had to get the rules a bit more clear, enough so that you know... And I think I need to be a bit more careful about how much information I disclose to the caregivers.[...] Because it's such a closed community around here and caregivers, like I find, that people aren't even often aware that they're breaching confidence. And I'll know, oh yeah, that's such and such they're talking about and they

aren't even aware. And sometimes I'll be good and let them know that I know that person and sometimes I won't be good and I'll listen to the gossip. Ha, ha, ha, ha, ha... And I guess the other thing is to know how that information is used.

For some of the participants in this study, caregivers are one of life's necessities. Activities associated with the everyday functioning of the body-activities that the majority of non-disabled people give little thought to - are a structuring feature of these women's days. Negotiating privacy and autonomy within the context of a professional yet intensely private relationship is fraught with difficulties.

Factors such as the severity of your disability, or the processes of ageing intensify this relationship. People reading mail, listening to conversations and answering phones, knowing who telephones and visits and generally having access to almost every aspect of your life, means that privacy becomes difficult to maintain. The participants make direct links between the possibility of establishing privacy and the body's physical capacities. Privacy was directly linked to the severity of disability by the participants:

Jane: But what I was going to say about the privacy thing is, well, what gets up my nose, perhaps not so much up my nose but, what is difficult is really not having privacy in your life. And the older you get and the more dependent you get upon somebody else because of your disability is beginning to worsen, then the less privacy you tend to have.

Kelly: ...so you know you don't get much privacy at all depending on the severity of your disability but its something that you just have to get accustomed to and sometimes it's hard for people to understand when they're used to doing things for themselves. [...]

Foucault's (1978:139) notions of '*anatomo-politics of the human body*' and '*bio-politics of the population*' can be used to theorise the issues raised in relation to privacy and sexuality above. In Foucault's analysis technologies of power work to produce particular kinds of disciplined subjects. The urge to confess (confessional discourses), regimes of surveillance, institutional practices (such as school timetables) and Social Policies themselves are examples of technologies of power.

The participants' stories and analyses suggest that technologies of power including discourses of confession (the desire for private intimate relationships) and discourses of surveillance (nosey carers), are operating in their lives. Such an analysis facilitates better understandings of how bodies are constituted, particular tasks are allowed or disallowed and thus specific kinds of subjects are produced (Gatens, 1992). In terms of sexual subjectivity discourses of asexuality and 'dependence' work to limit and define the boundaries of acceptable sexual expression. Resistance to the discourses of acceptable sexuality for women with disabilities is evident in the participants' accounts above. One way in which such discourses are resisted is through reinstating the importance of privacy. Morag stressed this point emphatically in her Life History interview:

Changes to the privacy legislation have prompted Morag to keep her medical files herself. 'I feel strongly about privacy issues and client confidentiality' .

Conclusion

This chapter has considered the notion of disability as discursively constructed by a plethora of competing discourses working upon, in, and through the body. Issues of embodied difference are considered in this thesis. Confessional discourses and technologies of power or surveillance were identified.

In this chapter the analysis focuses upon the ways in which embodied difference is constituted within relations of power. The technologies of power identified by the participants in this research include medical discourses, particularly as they relate to sexuality; other assessment and classification systems, such as those utilised by social welfare; and social expectations, such as being expected to answer personal questions and having too much or too little expected of you. The participants implicated such practices in their analyses of the marginalisation to which women with disabilities are subject. The analysis of non-disabled people's assumptions about and responses to people with disabilities, and of privacy and sexuality offered in this chapter, is summarised within a feminist postmodern framework.

In Chapter One, it is suggested that power works through the body in ways that reinforce the divisions between people with disabilities and non-disabled people. Confessional discourses are one means by which this is accomplished. By confessing our deepest secrets, or revealing the truth of ourselves, we are supposed to become free. However, a Foucauldian analysis of this suggests that such self revelation occurs within relations of power. Confession both requires the presence of an authority and is involved in the production of truth and knowledge⁴ (Foucault, 1978, 1980). This study and the literature written by women with disabilities suggest that interventions into daily life, in the guise of constant form filling, assessments of the body and bodily abilities for funding purposes, answering of questions about the intimate details of their lives, and interactions with carers, are often intrusive and leave little space for a private life.

In this study, it is argued that techniques of discipline and surveillance, such as confessional discourses, impact negatively on the lives of women with

⁴ See, Foucault, (1978:61) and (1980:216-217), for a discussion of his ideas on the subject of confessional discourse.

disabilities. The participant's analyses foreground the inadequacies women with disabilities face in a non-disabled world. Non-disabled responses to, and assumptions about disability, often begin from perceptions of the body and bodily abilities. Henrietta's comment that people think someone with a severe communications disability hasn't '*got anything to say on a particular - on any topic at all*', and Kelly's comment that when people see someone '*in a wheelchair they automatically think that you're dumb, deaf, and stupid*', illustrate this point. It is everyday realities such as this that demonstrate the salience of Liggert's (1988:274) suggestion that 'relentless refusals to go along with what appears to come naturally are the front-line battles in the politics of disability'. Despite the ways in which identity functions to mask the diversity of disability, the theoretical perspective forwarded in this study and the analyses of the participants both suggest that it is necessary to strategically claim identity, in order to *resist* disableist assumptions.

In this study, it has been argued that our embodied realities cannot be productively denied. An analysis of the sexed body is also relevant to this analysis. Having the body of a woman with a disability, rather than a man with a disability, has a certain meaning. The body of someone with a disability is sexualised or desexualised, on the basis of particular assumptions. It can be argued that the lives of people with disabilities are inscribed in multiple ways by the necessities of their bodies. Or to put it another way, that particular discourses are written on, or speak through, the bodies of people with disabilities.

The idea that discourses are spoken through the body is explored in postmodern feminist analysis (Kirby, 1991, 1994). Bodies are conceptualised not as conduits but as filters through which discourses are spoken. Postmodern feminist analyses critique the idea of the disembodied subject. In place of the disembodied subject, the proposition that our embodied subjectivities speak for us in multiple and diverse ways is forwarded. The question of who is speaking (arguing, researching, writing) matters. This critique calls into question the rational knowing subject of liberal-humanist discourse, raising objections to the ethnocentrism and phallogentrism inherent in such a conceptualisation of the subject (Mohanty, Russo & Torres, 1991). From a perspective such as this, it is impossible to speak from a disembodied position of unbiased neutrality.

Are the bodies of people with disabilities considered to be public property? The participants and the literature I have drawn on in this study *would* suggest that the lives of women with disabilities are subject to constant surveillance. The

participants talk of technologies of surveillance in terms of intrusions, such as constantly being required to define themselves in relation to assessment criteria and in relation to the ways in which a lack of privacy works to define their lives in particular ways. These practices can be analysed in terms of Foucault's (1978) analysis of the administration of bodies and the calculated management of life.

The administration of bodies produces particular understandings of disability. One of the major points made by the participants in this study is that non-disabled people's responses to people with disabilities often have their basis in ideas that have little to do with the realities of having a disability. The participants' suggest that non-disabled people's attitudes need to change if the situation is to improve for people with disabilities. In this thesis it has been suggested that non-disabled people's attitudes can be regarded as the expression of popular discourses on disability at a micro-level. Foucault's analyses of an '*anatomo-politics of the human body*' (1978:139) as an explanation of the ways in which power works to discipline the body, can be utilised in an analysis of non-disabled people's attitudes to people with disabilities. It can be argued that when non-disabled people relate to people with disabilities in inappropriate ways they are participating in practices of marginalisation. Power is exercised in a way that reinforces relations of power in which not having a disability is privileged over having a disability. The interpellation (or interruption) of relations of power that work to maintain the privilege accorded non-disabledness, is one of the major aims of this study.

This chapter can be situated within the context of sociological, feminist and philosophical moves to write the body back into theory (see for example, Irigaray, 1977, Martin, 1987, Sawicki, 1991, Shilling, 1994). These theories and the stories and analyses of the participants suggest that bodies do matter. In this study, it has been suggested that subjectivity and our understandings of selves are constituted through the workings of power on the body. The following chapter, Chapter Seven, considers stories and analyses shared by the participants, relevant to the theoretical discussion of selves undertaken in Chapter Two.

Chapter Seven

The Self, Caring, Politics and Power

Introduction

The self developed as a major category of analysis in this study. A theoretical journey through the literature on the subject and the self is undertaken in Chapter Two of this study. In this chapter it is argued that selves are constructed within relations of power. Some incarnations of selves are accorded more power than Others. Women and people with disabilities have traditionally been assigned the subject position of Other. Thus, this analysis of the self can be linked to one of the major aims of this study, the destabilisation of the binary between non-disabledness as hegemonic and the experience of disability as Other.

Selves are constituted through a plethora of competing discourses. The question of the limits of human agency or the capacity to resist is a popular topic in analyses of the self. The idea of privileging local struggle as a way in which individual agency might be expressed, is forwarded as a way in which the voices of selves who have previously been marginalised might be heard. Resistance at the micro level is forwarded as one way in which resistant discourse might be brought into circulation (Irigaray, 1977, Kondo, 1990). Micro level resistances such as Margaret's speech against the idea that life is what you make it can thus become a catalyst for political action:

*But life isn't plain sailing you know. Saying life is what you make it...
and in fact I hate that saying.*

'Life is what you make it', 'the level playing field' upon which we all have an equal chance of succeeding, these and other such popular clichés, are exposed by the participants as vacuous nihilisms throughout this study. The participants in this study also critique the opposite view where people with disabilities are seen as tragic victims in need of welfare support. In opposition to these unproductive discourses, a way of thinking that exists outside of non-disabled mainstream consciousness; that demands attention to material needs and access to everyday resources, is developing. In this chapter dialogues between feminist theory and the women who participated in this study intertwine to produce new understandings of the ways in which power produces particular permutations of the self. This analysis foregrounds power issues in the caring dynamic.

Caring needs and issues are an integral part of the lives of people who require carers. Caring therefore holds a central place with regard to constructions of the self. It would, for example, be impossible to construct oneself as a recluse, when having contact with people is not a matter of choice. Having carers also brings with it the need to become skilled at interacting with other people. An awareness that the skills needed to resist marginalising discourses are not easily acquired and are linked to class, and life experiences generally, emerged in this study. The participants argue that providing people with disabilities with the skills to negotiate factors, such as relationships with carers, and other aspects of living in a non-disabled world, begins with adequate education and access to necessary information.

People with disabilities are working on a number of levels to subvert disabling discourses and provide more spaces for the crafting of selves. Kelly's comment below captures the attitudes expressed throughout this study. Rather than dwelling on the negative, an ethos of working with situations that are less than acceptable and turning them into something positive prevails:

Kelly: [...] The video that I'm doing is um, creating scenarios and saying, well this is wrong, but we're making the best of it. It's creating a negative situation and turning it into something positive because what I didn't want to do was to illustrate, people, um people with disabilities, that's the political term, as a bunch of complaining people who sit on their bums all day. OK the situation isn't that great but people are making the best out of it [...] By doing that I'm hoping to change people's attitudes not to say this is wrong and this should be changed.

This study begins from the question of 'what am I... for her'. This question, is a postmodern question, the origins of which can be located in the work of Probyn (1993) and Foucault (1982). More specifically the origins of this question can be located in Probyn's reconceptualisation of the Cartesian question of 'who am I...', 'who is she..' with the question of 'who am I... for her?', and Foucault's (1982:216) *what are we? in a very precise moment of history... as an analysis of both us and our present*'. In this chapter, this question translates into an interrogation of power issues at the micro level of the everyday caring needs of the research participants. This analysis begins with a discussion of relations of power and powerlessness as they apply to the problems the participants experience with their caring agencies.

Caring Agencies

The ways in which power works in relation to caring needs can be seen in the participants' analyses of caring agencies. The participants' views on caring agencies were largely consistent with one another. Caring agencies are the most universal or institutionalised aspect of requiring full time care. In this study it is argued that selves are constituted within relations of power. Taking Probyn's (1993) idea that the self both expresses the specificities of local power relations and allows us analyse them as a starting point, agreement on the subject of caring agencies could be regarded as a demonstration of the ways in which particular discourses impact upon constructions of the self. Agreement over the ways in which caring agencies are conceptualised, suggests that the participants have come to understand themselves in relation to caring agencies in particular ways.

All the women who took part in this study live independently in their own homes. However, all require help with everyday tasks, at some level. Some require home help to cater for their physical environment, some require intermittent or occasional personal care and some require regular daily personal carers. The level of care required by the participants varies. Some need carers in order to get up and get out of bed in the morning. For others, carers speed up the process or make it less tiring thus enabling them to spend their days more productively. Some of the participants have their carers supplied through caring agencies and some employ their own carers. This topic stimulated heated discussion. Regardless of their own personal care requirements, the participants expressed strong opinions about caring agencies. Dissatisfaction with existing care provision takes a wide variety of forms:

Stacey: Agencies, never again, wouldn't touch them. I've had enough experience there.

Margaret: Yeah, I think the agencies just, I might be wrong but I've quite often come across people who care for someone and there only they're about two weeks. I think if you're going to care for someone you have to go the whole hog and, I don't know.

Margaret: That brings up another point too, about district nurses, there's a lot of times when I want to tell them where to get off but I

need them. But at the moment I need them so I can't lock the door and tell them to... go away.

The interview with Henrietta, cited below, was interrupted by a call from the agency that provides her with carers. The following excerpt is Henrietta's response to this telephone call:

It takes the spontaneity out of my life the fact that she thinks she can draw up a roster till February. You know. And it's all nice and tidy just a little box, morning, lunch, tea and bed. You know where you're going to be at certain times and on February the 5th you'll have so and so. Ha, ha, ha, ha... and it takes quite a lot to try to work around that and still maintain some spontaneity without...

Caring agencies provide a necessary and important service for people with disabilities. However, the participants suggest that people with disabilities have very little say in the running of such agencies.

An absence of appropriate training for carers is another major issue. As the main providers of carers, caring agencies are in part held responsible for the inadequacies of carers:

Stacey: I agree that people have got expectations. People don't understand the disease that's what it boils down to. People on a job like this should go out and have training. It makes sense.

Margaret: Right, I think it's really important that, um. Looking after someone is a very stressful job which I'm sure I don't need to tell you. Um, I think... there's a special person, sorry I think it takes a special person to have a carer's job whether it be for a child an adult, an elderly person, someone who's dying. I think not enough care is taken to... I don't know, um, try to find that person... I don't know.

Stacey: Now I had someone to help me put on these great big plastic feet thing that I've got on at the moment. UFO's I call them. Just those plastic moulded things to help you stand. Just say somebody is picking your foot up. Their automatic expectation is that you can hold your foot there, or you can put it where it's supposed to be. But you

*often can't there's just no way you just haven't got the power for it...
They don't know, they don't understand.*

The rhetoric of caring agencies represents the people who receive care as clients. However, the participants' descriptions of the everyday lived realities of their lives suggest that these so called *clients* have little say in, or control over, service provision. It can be argued that in failing to provide a service that clients are happy with, caring agencies play a role in the communication of disableist discourses.

Power and the Caring Dynamic

The following analysis of power and the caring dynamic begins with a description of the way in which this theme developed. This theme is introduced in this manner because, in this case, the way in which the analysis of power developed in relation to discussions of the caring dynamic is revealing in itself. Issues to do with power were raised in the Life History interviews. These were written into the interview guide for the follow-up interviews.

The theme of power and the caring dynamic discussed below, developed in response to questions raised in the follow-up interviews concerning high levels of uncertainty in the living circumstances of people with disabilities. The discussion progressed over the course of the interviews to a further analysis of the dynamics of the caring relationship. The participants articulated nuanced understandings of relations of power in such situations. Critiques and analyses developed in discussions about caring agencies and in descriptions of relationships with the carers themselves. Discussions of power in relation to care directly addressed themes such as fear, threat, and control. Henrietta's altercation with her caring agency (described below) was the catalyst for many of the comments made in this category.

In Chapter Two it is argued that the self can not be understood as an isolated entity, rather the self (and selves) must be recognised as constituents of community (Trinh, 1989, Haber, 1994). For the participants in this study who require full time care, carers are a large part of their everyday community. The following discussion is illustrative of the ways in which selves develop in conjunction with relationships with carers. Having carers as an integral part of everyday life means that it is necessary to always be in a frame of mind to deal

with people. Having an off day, or wanting time to yourself are not realisable options. Alongside this there exists the problem of finding compatible carers, who are physically capable of looking after people who need to be lifted. People who organise their carers through caring agencies are reliant on the agencies to provide capable and experienced carers. Henrietta provided an example of what can happen if problems develop between the person needing the care and the agency:

Henrietta: Certainly, it's a very real threat. I felt like that at the beginning of last year when we didn't seem to be able to get a stable team at all. And when Iris rang and said I don't think we can meet your personal care needs. I guess the threat was implicit. But, the reality of it for me was, if I don't have attendant care. You know, the other home help agencies are worse. Um, much less reliable and consistent. You know attendant care with all its warts is still the better of all the options. And that was going to be the next logical step that I was going to have to return to some form of institutional setting. It was not a pleasant thought. And it was a matter of actually challenging her on that and saying you realise what you're saying? That if you're saying attendant care will withdraw my care, this is what it means. Really having to spell that out and it left me feeling very vulnerable... very vulnerable...

The participants, even those who do not have full time carers, considered Henrietta's predicament to be outrageous. Indignation and comments such as, 'that's controlling', 'that's power', characterise responses to this issue:

Morag: That's controlling... and that threat of going back to an institution. A lot of people get tremendous kicks out of it, having that control. I mean I could talk and talk and talk Michelle and you probably know that. Sharing some of the experiences that I do have.

A more subtle but no less defining aspect of these women's lives is the need to organise your life around other people and other people's life styles. In other employment situations the employer determines the terms of employment. However, power relationships in the caree/carer dynamic are much less clear cut:

Jane: *Because you've got people around you all the time and you've got to all the time gear your life to them, like, even if you're going to go out in an evening or something like that you're gearing your life all the time to being home at a certain time, that your carers going to be there to put you to bed. And another thing is, that I really resent and I have had it especially I used to find when I had the district nurses in the mornings because there weren't enough hours in the care program for me to have a carer to do that in the morning.*

Margaret: *Yeah, well at present they come at night but its a hassle you have to wait around for them and sometimes they don't get here until 9 o'clock at night and its actually inconvenient especially if I'm feeling unwell... Which has happened on more than one occasion.*

Negotiating times that suit both the people who require care and their carers is only one aspect of the caring relationship. Relationships with carers also need to be negotiated. The process of building and maintaining relationships requires well developed interpersonal skills. Relationships with carers was another site at which power issues came to the fore.

Negotiating Relationships with Carers

Who has the power in the caring relationship? Although this was not the focus of the original question in the follow-up interviews it soon became apparent that this was a very pressing issue for the participants. Caring needs dominate the lifestyle options open to people who require carers. Discussions about power in relation to carers themselves also addressed issues, such as privacy, theft and dignity:

Margaret: *Yeah, yeah definitely... as far a district nurses go I feel I haven't got a lot of privacy and that really bugs me, but I mean... If I'm going to get through this... It's a bit of give and take on both sides I think... more on my side...*

Michelle: *Do you think you have more control over it... or them?*

Margaret: *I have to give up more, I have to be prepared to give up more.*

Stacey:[...] *She is the sort of kid who... it's my job let me do it, you know. So without getting into a conflict there I let it go.... I just sort of think if that happens too often no way. I couldn't be bothered with it you know.*

Stacey: *I suppose you do pick and choose. I will never have that system again; only having one home help. I want to be, as you say in control... It's much more flexible for me and for them.*

Of all the participants Kelly was the only one who consistently spoke of herself as the employer and the carer as the person dependent upon her for employment. Kelly offers a self conscious and particularly insightful analysis of the process of negotiating the caring relationship:

Kelly: [...] *you know, you're in control of them because you're telling them what to do, because you can't do it yourself. But at the same time they're controlling you because you feel vulnerable because you've got no privacy. So here they are coming into your home, you know, and that's very private, so you don't get much privacy in that respect. You feel vulnerable, you feel like they're in power over you because you're on your own, don't know what they're going to do and they could refuse to do certain things and stuff like that as well. It's like this if you're on the toilet and they're rude to you they could walk out on you and leave you on the toilet. This happened to someone I know. In a way it was the client's fault because she doesn't have a good rapport with people. And another time this other person didn't have a good rapport with her carer and the carer, even though she was a bit of a bitch walked out on her leaving her naked on the bed with just a sheet over her and that's the kind of power they do have. When you're not... when you're not mobile and you can't do things for yourself and you're naked. They have power over you because you feel vulnerable...*

Kelly: *I've had clothes nicked off me. I've had money nicked off me. And It's really difficult because like I said people come into your home. You're vulnerable, um, you know. You're in the shower, you want to have a shower alone so that leaves them to do what they want to. They could be any where and doing anything. I have a friend, her carer nicked off with her clothes and turned up wearing her clothes*

the next day. Now what she does is she drops the soap or bumps the wall so that they come running. Just so that she can check what they're doing and where they are. So yes it is an infringement on your security. Especially if you've given them a key or something you've given them an invitation to come into your home. You know people just seem to be genuine... but.

Another site at which a lack of power or control is felt, is in having control over who performs everyday personal tasks. Having familiar people who know what to do is a major aspect of this. Jane's comment that she likes things to be 'smooth and balanced' and Morag's comment on having a caregiver who knows her well enough to anticipate her needs, highlight the benefits of having the caring related aspects of everyday life well organised:

Jane: Personally I don't [like to have a lot of carers]. I like the carers to get to know my routine to be smooth and balanced in the way you're handled and if you've got a whole lot of people handling you then it can become very exhausting and I um I don't actually like it. I like to have 3 or 4 good people who I know well. Who get to know me well. Usually I find I can rely on that small network. Whereas if one can't then the other will be available to back up.

Morag: It's a bit like Veronica, who's my best friend or one of my best friends and I still find that really difficult, even though she is being paid; having someone in my home. To distinguish between the two, but I still find it difficult. I would never have anyone else in my home. She is absolutely superb. She is a model of what a good care giver should be. She anticipates me. She knows when I'm tired...

Henrietta: It takes more time with a new caregiver though. Um... I end up having to bite my tongue and tell them not to hurry up on the first date type routine.

A loss of dignity is associated with lack of control over who performs caring tasks. Experienced and familiar people are preferred in any setting:

Kelly: [...] if you have a disability you leave your dignity at the door and pick it up on the way out...as my mother says. And it's because I've got so many people caring for me.

Stacey: [...] if I have a hospital visit. There have been occasions when I've gone down hill. And I haven't been able to wipe my own derriere. You know things like that and it's very frustrating, very. As she said, (Jane) you get to the point. It's like going to hospital to have a baby. You leave your pride at the door on the way in and hopefully pick it up on the way out. You know... yeah.

Montague (1993) identifies a link between dignity and privacy in situations like those described above. She suggests that the feelings of people with disabilities about such issues seem to revolve around how much the person receiving the care feels they are in control of the situation and how much they feel they have to suffer a loss of dignity and control. However, regardless of the quality of the care and the level of control the participant's stories below suggest that they would prefer not to be reliant on carers.

A lack of autonomy, or control over who performs the caring tasks, can be linked to notions of independence that are based upon ableist notions of the autonomous individual. In Chapter Two the notion of the autonomous individual is called into question. In its place the self is presented as a constituent of communities (Haber, 1994). The dialogues between feminism and disability taking place in this study are intended to make links between the feminist community and the disability community. It can be argued that if women with disabilities were regarded as an integral part of the feminist community, caring might become a site at which feminist claims were more strongly or differently articulated.

An interaction between the perspectives of women with disabilities and feminism might produce quite different conceptualisations of what we understand as caring issues. Morris (1991, 1991-92) suggests that the failure of feminist researchers and academics to identify with the subjective experiences of those who receive care means that feminist analyses in this area come entirely from the point of view of non-disabled women. The participatory method utilised in this study begins from this suggestion and builds upon it. This strategy is achieved by beginning from the subjective experiences of a group of women with disabilities and integrating their ideas throughout the study. This strategy can be linked to Yeatman's (1994) suggestion that connections with those whose priorities are different from our own have to arise out of negotiated agreements. It is not enough to merely begin from the experiences of people

from, whom we differ in some way. The practice of negotiating agreements is one way in which communities of selves, in which differences both within and between women are taken into account, might develop. Thus the care of the self, is intimately linked to practices of caring for others for and within our distinct communities (Probyn, 1993). Munford's (1994) analysis, in which the experiences of caregivers and those who receive the care, combine with a problematisation of the ways in which disability is conceptualised and defined in society, points the way to the radical potentials practices of making links between the self and Others might engender.

Necessary, Needed, and Still Unwanted: Carers in the Caring Relationship

This section could have been entitled a necessary evil. Why? What does it mean to have other people as an ordinary part of even the most intimate aspect of your everyday life? Do people ever get used to it? 'Wanting' and 'needing' signify two very different events in the context of the caring relationship. 'Can you go to the toilet for me?' might be a smart reply, or a genuinely felt request when we are so tired or so comfortable that we don't want to move. But needing someone to take you to the toilet is a different issue. The subject of carers not surprisingly elicited a wide range of emotional responses from the participants. In the Life History interviews the experience of needing carers was variously described as: *stressful*, an aspect of disability that requires careful *negotiation*, as a limit upon *spontaneity*; and as *defining* of lifestyle choices. Carers are necessary and needed, but given the choice, still unwanted:

Kelly: At first I hated other people caring for me, I was conscious of it, but now I'm not. I have the assumption well, if I want to have a shower I've got to have someone to help me. If I don't have someone to help me well I can't have a shower. It's the same if I have to go to the toilet so I have to put up with it. It doesn't bother me now. Even my friends or my flatmates if I want to go out at night they're quite willing to put me to bed at night. I don't care if I sleep in my clothes...

Stacey: [...] there have been occasional times when I have really required somebody and I really required somebody urgently. Or reasonably urgently and I had an accident one morning as far as urinating. Now that to me was really... I felt like dead you know it was

that bad to me. Here I was trying to clean it up anyway. You know, but to my way of thinking that wasn't cleaned up enough. Not nearly. So I was relying on somebody who was not a total stranger because they'd been here for a long time. Relying on somebody else to do that sort of stuff. I don't know... I guess I'm just too independent in a lot of ways.

[...] But I felt like a big baby. It's a horrible feeling. If it was me doing it for somebody else I wouldn't hesitate. But it's just such a horrible feeling you know and you are relying on them to even be there. I was terrified she was going to ring and say she couldn't be there. This was between about six and nine. So in the meantime I was slopping water everywhere and stripping beds with one hand. It's kind of difficult believe me. But you just sort of think oh please don't say you're not coming. I was really dreading it. I was relying on her.

Margaret: It was recommended to me that I get attendant care. But I said no to that. For the simple reason that I would be having people going in and out of my house all the time. I want one person in my house and one person only... Beth is wonderful. I've had four home helps and she is my best one.

Henrietta: That about sums it up. From my experience in an institutional situation and certainly where carers come in regularly, like for me um four times a day, they are a necessary evil and they can certainly be an intrusion. And um you have to weigh it up, like if I'm with someone else am I going to get them to do the caregiving role and cancel the caregivers, baby-sitters, or umm have the carer come in and do her bit an off again kind of routine and either way I think it, probably getting the friend or visitor or whatever to do it is probably easier if that is possible. Because otherwise the caregiver tends to feel quite uncomfortable too. Sort of not knowing quite where they're going to put themselves. Some of them are better at it than others. One young woman I had, she was really good and you know like and quite often someone would ring up at tea time and come around with a bottle of wine and she'd just sit and go on, you know, cruise on. Just get the washing do the ironing or whatever, sort of just yeah, merge in with the paperwork and then just go. But others, you

feel like you have to entertain them or just get rid of them. One or the other...

Being dependent on other people to perform everyday tasks is an everyday aspect of these women's lives. However, being dependent on other people is also something that the participants in this study strongly resist. As Morris (1991) suggests, the issues around dependence and independence, are complex and important ones for people with disabilities. 'In terms of the physical world, none of us - whether disabled or not - is completely independent in the sense that we rely on nothing and no-body' (Morris, 1991:137). Independence has to do with having control over various aspects of your life. In the extracts above having familiar and competent caregivers emerges as an important aspect of establishing independence. The ways in which the material aspects of having a disability impact upon the construction of selves is discussed in the section below.

Disability, Politics and Selves

The topics covered in this final section concern the material aspects of having a disability, such as the ways in which selves are constructed in relation to community, and education and mainstreaming. These topics emerge from established issues in disability politics. These themes are easily identified, tangible components of the factors affecting the constructions of selves for people with disabilities. Close attention to the construction of selves within such discursive spaces provides insight into how selves are crafted within, and in opposition to, a society structured by non-disabled sensibilities.

The Material Aspects of Having a Disability

Disability politics aims to destabilise discourses of disability as a personal tragedy (Oliver, 1990, Morris, 1991). Oliver (1990) presents these concerns through a 'social theory of disability' in which the needs of people with disabilities are presented as a problem for society rather than the problem of the individual. Heightening awareness of the material aspects of having a disability is an integral part of this challenge to the non-disabled world.

In this study questions about the material aspects of having a disability revealed that some aspects of having a disability can be mediated by changes in material circumstances, or access to the right resources. Other aspects of having a

disability (as Morag's experiences below illustrate) such as taking time to get up in the morning are less easy or impossible to manipulate:

Even getting out of bed in the morning is a challenge. It takes two and a half hours to get out of bed in the mornings. A lot of shaking and jiggling, affectionately termed the 'electric blues' accompanies these early morning activities (Excerpt from Morag's Life History).

The material aspects of having a disability and the ways in which these impact upon constructions of the self is the major focus of this section. Planning, organising and routinising were identified as ways in which participants improved the material circumstances of their lives. Fair and appropriate allocation of scarce resources was identified as a major issue. Problems to do with resource allocations such as, choosing between expensive resources, and procuring expensive goods and specialist services, were identified. Mistakes made by non-disabled people in making provisions for people with disabilities, often the result of insufficient knowledge or lack of planning, were also a major source of frustration for the participants. The issue of finding a truly accessible disability toilet is a case in point. Disability toilets are an established feature of standard building codes. However, the provision of a disability toilet does not necessarily guarantee that a person with a disability will be able to use that toilet. Reasons such as the hand rails being on the wrong side or being installed upside down, not being able to fit a carer and the wheel chair into the toilet, and not being able to open the door again for the carer to get out were cited by participants. My own experiences of swinging from the pelmet over the door frame in order to leave someone alone in the toilet in the Aotea Centre in Auckland is a pertinent example.

Stacey: [...] *Or, the door won't close when there's a wheelchair in it.*

Michelle: *Or the hand rails are on the wrong side.*

Stacey: *If they've got any hand rails... Are you supposed to hold the toilet role holder maybe! You know, I think they've got to be aware too that people with disabilities... you're going to get lots of different people. And OK, I really prefer to have something I can hold onto in the toilet. Otherwise that can totally wreck the whole set up for you, you know.*

Some aspects of living with a disability are more easily mediated than others. Having the correct wheelchair or means of transport can make an enormous

difference to a persons life. For Stacey an electric wheelchair makes all the difference:

Stacey: [...] There are times when I'm just too stuffed. Now the other day this chair needs to be repaired [...] the difference in me it was just incredible. Now in this chair I [can get tea ready]. But then you see I got back to the other chair[..] . And man it was like trying to heave a ton weight around. People think she can do this or she can't do that because: But they don't see just something small that will change the whole situation, like the chairs.

Henrietta: [...] The thing is it used to be that they expected that a wheelchair was supposed to last five years. Now there's been no significant change in the technology of the whole bit. It's just that at \$6.200, the monetary people have decided that we can expect that the wheelchair can now last for six years instead of five, without looking at it. You know the sort of use of the wheelchair. So the way that I use my wheelchair might be quite different to the way that someone who is in an institution uses it, in linoed corridors. And that's probably all they use it for. And they're probably not allowed to take their wheelchair into town because they might tip themselves on the footpath type routine, you know, etc, etc. So in fact you could probably expect to get about seven or eight years out of a wheelchair at that level of use. Compared to mine where you probably should be trading it in after three years. Not quite but, ha, ha, ha... But that, 'please Sir can I have some more', I'm a worthy cause, etc, etc... An now of course you've got to insure your own wheelchair.

Kelly: Just all the things that it costs for alterations and equipment and all that. My father works for a company where he can provide all this equipment; chairs and nick-nacks that could help me around the house, but because I'm not covered by ACC I can't afford it. Most of the stuff is really expensive. This cushion is worth \$800.

Michelle: A cushion, how come?

Kelly: I don't know. That cushions worth \$680. This chairs worth \$4000. My alterations were \$32 000. And if you have things that have to be on at night then your power bill can suffer too.

Henrietta: *For somebody like me where everything is means tested. I don't have any money allowed for mowing the lawn, for getting clothes made and so on. But certainly, you know, for anybody... And I've worked with families where the child is incontinent or the teenager is incontinent. And they're facing situations where mothers can only deal with so much. Having to replace mattresses often. And they're expensive little items mate. Um your clothing, is washed much more regularly. Even for myself, particularly in the summer time, quite significant difficulties with heat and that. So I'm having complete changes twice, sometimes three times a day. You know, that's a lot of washing mate. You know power bills and water rates and washing powder and the wear and tear on your home. And for me having the Securitas alarm system there's a rental fee for that each month and um... The... and the little things as well, when you've got heaps of caregivers coming through. I'm pretty civilised actually, I offer them a cup of coffee from time to time. But that's a significant expense, it's not one that I begrudge, but it's one that is there. And you sort of look at it. Putting the motorised chair on charge each night. It's not a significant cost, but it is there. You've got things for the car... That is expensive. And if you haven't got the same level of mobility then you're having to use your car more often. You haven't got that choice value to the same extent. Like, I'll walk to work today, or I'll ride a bicycle, or I'll take the car.*

One way in which the participants in this study mediated the material aspects of having a disability was by developing good planning and organisational skills. Timing is an important factor in the success of such plans however, as Margaret suggested in her Life History interviews, small time lapses can have major impacts:

'It's the time factor, doctors, taxis... it's hard having a job if you have to rely on taxis. . . If I'm late back to my job from appointments it doesn't make a good impression.'

Jane: *Life is geared to planning the whole way through. You never stop planning from one day to the next. I've got to be here tomorrow such and such a time and I've got to get my routine in order to be there. And who have I got to call on to get me there and how am I going to get there and whose support am I going to call on while I am*

there. Um, so you never stop. As the years go by you get good at it and you can work your time into a pattern where you get the most out of it. But the crucial thing is at the beginning of the day, if your attendant carer is running late at the beginning of the day that's going to put you out for the rest of the day and no matter what you do to catch up you can't. And it's no good [the carer] coming in a rush and expecting to be able to speed up the process in getting the person out of bed because that speeding up just exhausts many of us. We've still got to get up at the same pace we do anyway. There's just no short cuts to the system for us. There just aren't.

Kelly: Taxis are a pain in the bum when you're late. But other than that I get so wound up and so stressed out I make myself get there on time. I plan and organise, in advance so that I can get there on time it just makes it so hard when the bloody taxis so late all the time. When my carers are running late that pisses me off. Especially in the morning because I can't do anything until I get up.

Henrietta:[...] waiting around waiting for taxis and that sort of thing was just absolutely diabolical and you could wait for hours... literally... dead time. Waiting... for... a... fucking... taxi... (said through gritted teeth). Um, waiting for people if the caregivers late... It is time consuming.

Crafting selves around disability is a process that is intimately linked to other people. Therefore having the skills to establish the importance of timing and routine and to negotiate your needs around these factors is an important aspect of crafting selves in relation to having a disability.

Dematerialising the Tampon

It cannot be denied that the physical surroundings and material circumstances people with disabilities experience have an enormous impact upon quality of life. One line of reasoning forwarded by disability theorists, proposes that the problem for people with disabilities lies with society (Finkelstein, 1992, Oliver, 1990). Taken to its logical conclusion this position suggests, that if society was structured according to the needs of people with disabilities, then non-disabled people would be the ones with the disability. The position most strongly articulated by the participants is that although some of the material aspects of having a disability can certainly be minimised with the right resources, they

cannot be merely theorised away. In this study the material aspects of having a disability are intimately linked to the workings of the participants' bodies:

Henrietta: Yeah, and it's like that stuff by Jenny Morris where she sort of says that you can theorise disability off the planet. And it's no longer there. And you can remove the personal elements from experiences that people have. You know, [...] I guess part of it... Michael Oliver would probably respond and say, it's the way that society has been structured that does mean it's become more expensive and that the costs that are incurred are not recognised within the capitalist structures and so on and so on. Or not addressed and um. If society was structured different[ly] it wouldn't be such an issue but the fact of having to have caregivers looking after your personal care and their being in there in the toilet with you and they have to put the tampon in is very much a reality and no amount of theorising and subtle changes is going to change that. You might change the way people approach those tasks to a certain extent and hopefully reach a higher level of dignity and respect within that. But the reality is still there. That you're going to have to do it.

Stacey: Well you lose a lot. The amount of tampons that I've lost down the toilet. You've got to have balance to be able to manoeuvre with these things.

Stacey: Yeah instead of a half hour shower or twenty minute shower at most, you're in there for the best part of two hours.

Morag: It's, it's ... to summarise it's not leaping out of bed are your Macleans¹ showing. Remember that add...?, it doesn't work like that. So it's a complicated process of getting yourself ready in stages in the morning.

The material aspects of being friends with someone with a disability can be perilous:

¹Morag refers to a television advertisement for toothpaste, in which a woman bounces out of bed in the morning displaying her shiny white teeth in a large smiling mouth.

Kelly: *I remember I was sitting in the lounge with the builder and I chucked a hot cup of tea... Sometimes I give John a black eye, he doesn't mind her laughs.*

In the paragraphs above the participants suggest that some of the material aspects of having a disability are avoidable, some can be mediated or resisted, but that others cannot be theorised away. Postmodern theory insists that 'lived experience' must be viewed as itself a 'living out' of various discourses and cultural modes through which the subject is 'individualised' (Soper, 1990). A postmodern analysis would suggest we understand the material aspects of having a disability in certain ways according to the ways in which they are produced by the discourses surrounding disability. This emphasis on the role of discourse allows the deconstruction of disabling practices such as society's failure to recognise the time constraints many people with disabilities face each day. However, this analysis, like the analyses of Oliver (1990) and Finklestein (1992) above, cannot theorise away every material aspect of having a disability. As Morag suggests - '*it's not leaping out of bed are your Macleans showing.*' - some things need to take time and tampons still need to be inserted. My failure to find a position from which it is possible to definitively ameliorate the material aspects of disability leads me to support Morris' (1991) position that there are negative aspects of disability which would persist regardless of the kind of society in which we lived. Morris (1991:71) presents us with the idea of valuing and taking pride in disability, while not denying the 'awful things about disability' and difficulties associated with it. The participants' stories and analyses also suggest, that although having a disability is not a reality that would be chosen, there are positive things associated with the experience of disability and that these aspects of having a disability need to be valued.

This study calls into question the production of non-disabledness as the norm and disability as the Other. Feminist analyses of woman's position as Other or as lacking positive male attributes are utilised in this critique of practices of Othering. The idea of the self as multiple and contingent is forwarded in the place of the idea that it is possible to define woman or disability as a singular and universally knowable entity. The participants in this study offer support for the idea of the self as multiple and diverse by presenting themselves as more than the sum of their disabilities.

Disability literature also supports the idea that people with disabilities should not be defined in relation to their differences from non-disabled people. Ballard

(1994) suggests that many people with disabilities have rejected notions of 'normal' and the idea that people should be 'accepting' of difference. Instead the need to positively value diversity and ensure that each person is respected for who they are, not for particular achievements relative to others is stressed. This rejection of the 'normal'/'difference' dichotomy would suggest that the strategy of valuing difference has not proved to be productive for people with disabilities. Normal is still unproblematically situated at the privileged end of the binary. Yeatman's (1994) contention that in comparison with the integrity of the master subject woman's identity always appears as a lack, is useful at this point. Disability theory, feminist theory and the participants would all agree that defining one thing in relation to something that it is not (disability to non-disabledness, woman to man) should be rejected. Integrity can instead be claimed on the basis of multiple and situationally specific criteria.

It can be argued that, this critique of the ways in which disability is produced or constructed through discourses of disability (that define it as a lack) and the problems associated with the material circumstances people with disabilities find themselves in, destabilises the idea of disability as a personal tragedy. Thus some of the aims presented in Oliver's (1990) social model of disability are fulfilled, and the discursive boundaries around possible constructions of the self are widened. The locus of the problem shifts from the individual to the community. While expressions like 'community spirit' or 'a sense of community' have pleasant connotations for most non-disabled people, the excerpts below demonstrate that the concept of community may not inspire such positive reactions from a person with a disability.

I'd like to know whose community they're talking about?

In the theoretical analysis of the self (presented in Chapter Two) it was suggested that the opposition between the personal and the political be replaced with the notion of the 'subject-in-community' (Haber, 1994). Such a strategy allows us to see the multiple definitions of selves in specific situations and the inseparability of those definitions from specific, historical, cultural, and political contexts (Kondo, 1990). The ways in which power works through discourses that provide inadequate information and promote uncertainty producing particular permutations of selves, is illustrated in the stories of the participants below. These stories present selves who differ markedly from the selves described in other places in this analysis. The material aspects of disability especially in terms of where you live, how you live and who you live with, have an enormous impact upon the possible permutations of self.

Debates around deinstitutionalisation and community care policies are familiar terrain for most of the participants in this study. The themes that developed in this section reflect the issues commonly raised by such debates. Inadequate resources and inadequate support from the community emerged as two areas of concern. Deinstitutionalisation is widely regarded as a positive move for people with disabilities. However, the resistance to, and critiques of, deinstitutionalisation recorded in this study support Foucault's (1982) contention that apparent freedoms may not be as liberatory as they seem:

'Living [in the residential setting] was a good stepping stone, but it was actually worse than [the institution] in a lot of ways. The caregivers were untrained and slack. They had no respect for peoples' rights and privacy' (excerpt from Henrietta's Life History).

The participants suggest that the experience of moving from an established and known institutional community, to an unknown non-disabled community is ridden with uncertainty and anxiety. Lack of information and loneliness emerged as two distinct aspects of the experience of changing communities. Many of the comments on deinstitutionalisation and community care presented below were made in response to the following extract from Margaret's life history:

Margaret's first forty-eight hours in her own place were very different from her previous life. She had no telephone, no television and nobody else to talk to. The strangeness and loneliness of the situation upset Margaret, and she shed a lot of tears in those first few days. 'I used to sit in the corner, listen to my tape deck and bawl my eyes out... all of a sudden I was out in the community and it was good... but I didn't know anybody from Adam and [after the telephone was installed] I used to ring up my friends and bawl'.

Information in this section is drawn from the first hand experiences of the participants and from the stories of their friends. Of all the participants only Stacey passed over this topic:

Margaret: I've moved out of an institution twice in my life. But I've gone back. This is my third time lucky and I've been here four and a half years, but OK, I was younger then. A lot younger. I think if you haven't got the resources out there of course you're not going to try

and make it work. You've got to have the support behind you first if you make up your mind that you've got to go out to the big wide world that could be all fine and dandy. But if the resources aren't there you're just going to end up back in an institution, back where you started. I've been there.

Henrietta: Even for me transferring from [an institutional] to [a residential setting]. When I left [the institution] I had \$65 dollars to my name and I wondered whether I'd have to buy bed linen and furniture, all of that. So I think there's a lot more sort of stability and predictability in those situations now, where people do have an idea of what to expect, than in those days. The systems are I think better set up now for people making that transition, than what they were.

Jane: If you're going to move out of an institution into the community, a lot of these institutions they have set up programs to, to, prepare, um, those who are going to live in the community so that they can cope. But the programs are so damn ridiculous. [...] There's no back up, nothing. And they wonder why so many of them fail and can't cope and need to get back into an institution because that training - that so called training, that they give them in an institution is ridiculous.

Another reason why deinstitutionalisation should not be accepted uncritically, and may indeed not be as liberatory as it seems, is that the people in the institutions may have little choice of alternatives:

'..Margaret is concerned that the number of alternative living situations people with disabilities have to choose from is dwindling. 'I don't agree that there should be institutions but where are they [the people who live there] going to go?' (excerpt from Margaret's Life History).

Jane [...] Your not asked it's just assumed that that's what you want. That you want to get out and you want to live in the community. [...] even places like [Templeton]. You've got people who have lived there all their lives, now we're talking about deinstitutionalisation, returning them people to the community. Which community is their community? That's not to say don't bring them out. But, you know,

lets take responsibility for the fact that is their community. Because we've completely removed them away from the community and all their contacts and relationship links that go with that.

The lack of resources to enable people to make the transition from the institution to the community is one aspect of this problem. Inadequate support for people once they establish themselves in the community is another:

Kelly: A lot of people with disabilities they haven't been socialised in the community. They don't know what's out there. There are a lot of things out there but people don't go out of their way to tell you.

Morag: I've seen tragedy happen because people have just been bunged out in the community. No budgeting skills no awareness of what happens....

A community can be defined as a site at which fellowship, co-operation, common goals and a feeling of belonging are to be found. However, when the women in this study speak of the community, they speak of the non-disabled community from which people with disabilities are excluded. Margaret and Henrietta were not the only ones to refer to 'the community' as the 'big wide world'. Where do people with disabilities place themselves within 'the community'? There is an apparent contradiction here between the participants' conceptualisations of community and feminisms' traditional insistence on community as a site of resistance. However, in a postmodern feminist analysis this struggle over the meaning of the term community might be regarded as a productive contradiction rather than an impasse.

Contradiction can be a site at which problems are puzzled over and new ways of approaching issues (rather than resolutions) are found. For example, the idea of productive contradiction is played out at the site of the rejection of the universal Subject of human agency. A common criticism of postmodern theory asserts that abandoning the level playing field of the singular, universal humanist subject also removes the ground on which we base our value judgements from under our feet. Therefore, how do we choose between 'good' and 'bad'? How can we substantiate our moral outrage at things we consider to be 'wrong'? How can we choose one politics over another? Yeatman (1994) suggests that instead of returning to the masculinist, ethnocentric, humanist subject, we ground our struggles in legitimate connections between differently positioned social actors

coming together to work on pragmatic emancipatory political projects. Ideas of 'right', 'wrong', 'good', and 'bad', can thus be put aside in favour of negotiating more appropriate or *better* solutions for the differently positioned political actors who are the constituents of a group or community.

In order to achieve outcomes such as those proposed by Yeatman above, it is necessary to be able to conceptualise the self as both multiple and communal (Kondo, 1990). If feminists wish to make links between feminism and disability then the very concepts of community and commonality need to be problematised in terms of the historical exclusion of women with disabilities from 'communities'. The participants negative feelings on the subject of community reflect their exclusion from and marginalisation within 'the community'.

Women with disabilities have claimed that feminist groups practice forms of exclusion. Klein (1992:72), a feminist film maker whose personal experience of disability began suddenly in 1987 asserts: 'there is clearly a conflict between feminism's rhetoric of inclusion and failure to include my disability'. The processes of separating 'women with disabilities' from 'women' in feminist research also reinforces this exclusion (Morris, 1991-1992)². Feminism's rhetoric of inclusion can often be witnessed in postmodern feminist texts that add disability to a long list of oppressions in an effort to illustrate ideas of valuing multiplicity and diversity. When little effort is made to discover what the realities of the everyday lives of these Others might be, this process becomes merely a mask for exclusion.

Gaps between feminist rhetoric of inclusion and practices of exclusion do not enhance the appeal of the feminist community for women with disabilities. Community itself is not a neutral concept. For women with disabilities the community is most often the non-disabled community from which they experience degrees of exclusion. In view of the historical exclusion of women with disabilities from the community, and from feminism, making legitimate connections or finding some minimum common - ground may not be an easy task. Asking women with disabilities to share their energies necessarily involves transforming feminist communities into safe communities. Effecting such changes requires an understanding of multiple definitions of selves as defined in

²Morris (1991-1992) offers an excellent critique of feminist research on caring suggesting that the separation of women, from disabled and older people, reinforces the non-disabled/disabled dichotomy.

relation to economic, political, cultural and historical factors. The participants' particular definitions of self in relation to communities and feminist disability theorists' critiques of feminism's shortcomings suggest 'community' as a site at which connections between feminism and women with disabilities might be explored.

Beginning from the Beginning: Children, Education, Mainstreaming

'The big wide world', was often used as a figure of speech by the participants to describe the uncertainty of the unknown world outside of disability culture. Policies that foster segregation reinforce the uncertainties people face outside of segregated communities. The participants situate the non-disabled community in opposition to disability culture. The known world, or culture, of someone who grows up in an institution or attending a 'special' school is very different from that of their non-disabled peers. Being outside of non-disabled culture is held to be a disadvantage. Negotiating non-disabled culture is fraught with difficulties when your life experiences situate you as a foreigner, outside of an unknown culture.

The participants consider that the right to a mainstream education is necessary if people with disabilities are to develop the skills they need to negotiate their way in a non-disabled community. Mainstreaming is an extremely important part of childrens' educational needs because aspects of psychological behaviour have no chance to develop adequately in segregated communities.

Questions about mainstreaming revealed a consistency in opinions and ideas suggesting that this is a well established and widely debated issue. The positive benefits of mainstreaming are certainly well established in the New Zealand disability literature (see for example, O'Brien, 1989 and Ballard, 1994).

Margaret: Yeah, as far as children with disabilities are concerned I don't actually approve of them mixing with their own kind...

Michelle: Yeah, you think they should be mainstreamed?

Margaret: If at all possible. OK, OK, there are impracticalities of it. There's some people who, some children who are not capable, and I can accept that. But just that... to shove them in a school where there's a whole bunch of kids with disabilities it's not how it should be... Because, it's not well supported it never has been...

Henrietta: *Oh, absolutely. I think it's about being involved in the community. What happened historically is that they were put with children with disabilities which meant that they were removed from their local schools or their local kindergarten... [...] In that situation children were completely removed from their family as well as their local community. [...]*

Kelly: *A lot of schools still refuse to have disabled kids so they have to go to special schools and when they go to special school they're at a disadvantage. [...] You know why? Because those who come from special schools; special needs schools, they come from different parts of the city and it makes it hard to socialise in that respect and also it's important to socialise because then they learn the social skills. Because when they're older you know um, they just handle things better. [...] And I also believe that if you don't socialise a disabled child with other able-bodied people they become withdrawn. They become naive and gullible and vulnerable. So you know, their social skills are important for survival and that's the only way you can do it. So even if they have to go to a special school maybe parents could let them get to know the neighbourhood kids as well. I found it really rough when I first went to...[a mainstream school].*

Mainstreaming is important because it can also provide people who have no experience of disability with an opportunity to understand what goes on in the lives of people with disabilities. Disability becomes less of an unknown entity and therefore a more easily integrated part of everyday life:

Kelly: *And also too, it makes it easier with your friends because at a younger age your friends get used to it and they know what it's all about. So they've got no problems as such when it comes to getting older because you know what flaming teenagers are like. Like for me I was in a special school to start off with and then I was in several classes and because I'd never socialised much apart from my sisters friends I found it very difficult to adjust especially when the other kids were jealous and things like that.*

Margaret: *[...W]hen I was growing up... I had a disability so [...] there were a lot of things I used to do that people were quite shocked about like going out and playing, I used to go out and play on the*

swings and jungle-gyms and stuff and just like, going to the park and things was just unheard of because you had a disability. Or if you were out with your friends and you weren't with your parents or whoever it was just you and your friends, you used to get looked at sideways because going out was just never heard of. People have ideas like people with disabilities should be shut away not necessarily locked away but. ... It was that old saying you know... you could be heard but shouldn't be seen... and that is one things that used to really get me.

The issue for the participants is not whether children with disabilities have the right to go to a mainstream school but how to get them there:

Morag: [...] I had an argument with a Minister last year over this Michelle. It suddenly occurred to me if you keep your child away from school what are you doing?

Michelle: Breaking the law.

Morag: Your child is a truant, you're breaking the law. So what gives the Minister the right to use his discretionary powers to not allocate those teacher aid hours so that our children can attend school just as every other child is entitled to, to be educated and fully empowered [...]. In essence people are keeping their children away from school because of the unavailability of teacher aid hours. Does that make sense to you?

The participants' accounts strongly suggest that non-segregated educational experiences are considered to be a foundational aspect in the drive to assert the rights of people with disabilities. This resistance to existing practices is being played out at the institutional and policy level. Practices of resistance at a more micro level can be seen in deployments of irony often evident in the language of the participants.

Irony as a Means of Resistance

Having a disability brings with it the need for skills in negotiating complex sets of systems. In order to access necessary resources people with disabilities are required to constantly interact with product and service providers. Commonly cited tasks include filling in forms for Government agencies or private providers and being subject to tests to determine the percentage your disability will be rated. These interactions are often regarded as intrusive and unnecessary. The

women in this study expressed a sense of frustration with regard to interactions in this area. Irony was often employed as a means of challenging or coping with such requests. Walking back from the kitchen to the lounge one of the participants commented with a wry smile:

I am now supposedly what they call only 10% functional. They increased my invalidity to 90%... I was reassessed... um. So I'm working on 10 %...

The participants' ironic humour does not negate the seriousness with which negative consequences of systems of classification are regarded. The statement above was made in conjunction with the following comment:

You challenge yourself. I mean I have days when you just are so bloody tired.... But you do you constantly challenge... If your were to do what the medical experts tell you....

Being classified as having a particular level of disability was identified as being psychologically damaging by the participant in the example above. Kelly, Morag and Henrietta's experiences of having to prove that your disability is still with you and that you haven't experienced some kind of miraculous cure, provide a particularly potent illustration of the frustrations experienced in relation to resource acquisition. Irony was employed as means of stressing the importance of the issue in each case:

Kelly: I have to go down there, show myself to them, just to prove that for 23 years I have been in a wheelchair. I mean for crying out loud I'm not going to get up one day and say, 'it's a miracle I can walk', so why don't they just leave it!

Morag: Yeah, yes stop sending me letters asking if I'm still using my wheelchair. I rang them up: - I've had two letters saying, 'if you're not using your wheelchair them please return it... ..So what I do now is ring up and say, "have you found a cure?!"'. [Be]cause I'm sick to death of it [...]

Henrietta: [...] And now of course the system has developed more hoops for people to negotiate, like in order to get the invalids benefit now you have to be 75% disabled. That's a big disability. And that's

*disqualified a lot of people who qualified for the invalids benefit whose lifestyle was significantly impaired by their disability. But now all of a sudden they no longer had a disability. A **miraculous cure**. (my emphasis)*

In Chapter Two a theoretical analysis of the uses of mimicry and irony was undertaken (Irigary, 1977, Moi, 1985, Kondo, 1990). The subversive possibilities inherent in strategies of resistance that utilise strategies of irony and mimicry were discussed. Kondo suggests that irony is a means by which resistances to power are articulated. Irony is a strategy that is used often and to good effect by the women in this study, and is a site at which micro level resistances can often be witnessed.

This chapter, on disability, politics, and selves, documents the participants' subjection to a wide variety of marginalising practices. The participants understand these practices of marginalisation as a complex process of exclusion from the non-disabled world. The various ways in which such marginalising practices are resisted is also documented. Resistance can be found at the micro and the macro levels, from the routine organisation of everyday life to arguments with members of Parliament. Foucault (1978) suggests that liberation can be achieved through such a plurality of resistances. Rather than searching for a revolutionary theory that promises transcendence, postmodern analyses suggest small acts of defiance as the strategies of the future.

Conclusion

This conclusion considers issues around the construction of selves within relations of power. Normalising discourses, the caring relationship, the material aspects of having a disability, power issues, autonomy and the concept of community are discussed with reference to their relevance to the construction of 'the self'.

Numerous examples of the ways in which normalising discourses are communicated and resisted have surfaced in this chapter. The caring relationship developed as a site at which issues to do with power were clearly articulated. An analysis of power relations as they impact upon constructions of the self developed from this theme. Power relations within the context of the caring dynamic play an integral part in the process of crafting selves. The participants articulated a number of critiques of and resistances to, the ways in which power works through the caring dynamic. Resistance to practices of marginalisation provides spaces for the crafting of selves outside the boundaries of non-disabled expectations.

The participants offer numerous examples of the ways in which power works through discourses of disability and femininity to structure their lives in particular ways. A wide variety of resistances are also documented. The practices and philosophies of non-disabled people are rejected or subverted by people with disabilities in a variety of ways. Non-disabled conceptualisations of disability have changed markedly in the last decade. It cannot be denied that changes to the physical environment have enabled people with disabilities to participate in non-disabled culture. However, not all the changes have been successful and all are not regarded positively. Some of the most tangible of these changes such as the provision of disability car parks and EEO (Equal Employment Opportunity) policies are approached with some cynicism by the participants. The Life Histories and the follow-up interviews revealed a basic distrust of such policies which were often analysed as paying lip service to disability issues, or public displays of political correctness. Alongside this critique of existing policies people with disabilities can be seen to be politicising their demands in ways that can no longer be denied by non-disabled society.

In this thesis it has been argued that 'the self' cannot be understood as an autonomous entity. Instead the idea of the self as a constituent of communities is

forwarded. Relating this idea to the lives of women with disabilities, Dossa (1990) argues that the notion of the independent individual understood in terms of the self-determined rather than socially determined individual has negative repercussions for women with disabilities. The participants' experiences of isolation when moving from an institutional community to the non-disabled community, support Dossa's analysis. Dossa suggests that the notion of the autonomous individual maintains the clear cut distinction between the individual and the community. This study would suggest that this can be analysed in terms of the self, divided from itself, and from others. In this case the dependence/independence dichotomy fashioned according to non-disabled sensibilities functions as the dividing principle.

Drawing from a variety of theoretical sources, Dossa suggests that a community model of interrelatedness and interdependence will enable women with disabilities to engage in sharing and reciprocal relationships. The notion of the subject-in-community (Haber, 1994) can be related to this idea of the socially determined individual. These theories may direct us towards better options for women with disabilities. But what of the exclusions inherent in a concept of community? The information shared by the participants raises the question of who the concept of community *excludes*. Exactly whose community are we talking of? I argue that we need to move beyond the rhetoric of inclusion to a politics of inclusion. However, the constructs upon which these politics are based also need to be called into question. As Yeatman (1994) suggests, nothing, even good intentions, are outside of relations of power. Constructions of the self within and outside existing discourses of femininity and disability can be analysed in terms of politics and power. From this perspective, Haraway's (1988) situated knowledges and privileging of partial ways of coming to know the world make sense. This analysis of the self as a political actor and actant is developed in terms of its relevance to feminist research, feminist politics, disability politics and social policies in Section Four of this thesis.

Conclusion: Section Three

Society sets up a wide range of barriers that work to exclude women with disabilities. The processes of marginalisation and exclusion are wide ranging and pervasive. In each of the three chapters in this section the participants provide analyses and stories of resistance to the disabling discourses that contribute to these experiences of marginalisation and exclusion.

The meanings, functions and uses of identity categories were analysed in Chapter Five. Identity politics were not rejected in this analysis. However, the idea that people with disabilities are somehow fundamentally different from non-disabled people was. The overall impression I gained from the participants was that although disability does not define their lives it is, nevertheless, ever present. While having a disability is difficult there are positive and negative aspects of life with a disability just as there are in life without disability. This chapter could have been entitled 'Hey! we're not *that* different'.

In Chapter Six the body emerges as a site at which disabling discourses are conceptualised and communicated. Attitudes were identified as a major obstacle people with disabilities face. Non-disabled people are strongly implicated in these practices and participants articulate a variety of resistances to the tyranny of the non-disabled norm. The participants challenge the discursive construction of non-disabledness as the norm and disability as the marginalised Other. The body becomes a battlefield upon which meanings, such as the negative connotations disability currently attracts, can be productively contested.

In this section the analyses of identity and the body come together at the site of the self. The material aspects of disability, and the power and caring emerged as two particularly notable aspects of this chapter. Discussion with participants revealed that the material aspects of having a disability are perceived to be the most easily identifiable, quantifiable, and therefore, redressable factors in creating a less disableist society. The problem, the solution, and the ways in which solutions might be pursued are all considered. A comprehensive analysis of power issues as they relate to caring needs revealed itself as the major issue in this chapter. Dialogues between feminism and disability proved particularly productive at this point. These strategies are designed to destabilise the dichotomy between non-disabledness as the norm the experience of disability as Other. The success of challenges such as these remains to be seen. Like racism

before it, ableism and disableism are being brought out of the cupboard and into the public eye.

Section Four:

Reflexivity in Motion: Looking Forward and Looking Back

Introduction to Section Four

The final section of this thesis considers the outcomes of this study in terms of the future for feminism and disability. This concluding section is divided into two chapters. Chapter Eight focuses on methodological issues, and Chapter Nine considers social policy initiatives and other practices involved in the Othering of women with disabilities.

In Chapter Eight, I reflect upon the postmodern feminist participatory method utilised in this study from a postmodern feminist standpoint. Postmodern feminism is concerned with the revaluation of local knowledges and the production of specifically located and self consciously partial theories. In this study, these principles are set in motion in the creation of dialogues between feminism and women with disabilities. To this end, a research practice designed to make links between the ways in which the participants make sense of their worlds, and a particular postmodern feminist perspective, was developed.

The self-reflexive analysis of the method developed in Chapter Eight is undertaken with a view toward future research projects. Both the method, and the specific way in which the method was used, are rigourously scrutinised. It is argued that the ways in which the method was utilised, the presentation of the method, and the writing practices used in this study all affect the ideas that can be drawn from the research, in particular ways.

In Chapter Nine, I make connections between a variety of issues raised over the course of this study, all of which can be implicated in practices that Other women with disabilities. Discussion in this chapter is undertaken with a view towards the possibilities that dialogues between feminism and women with disabilities might inspire in the future. This analysis has its foundation in feminist postmodern interest in local and specific knowledges, and is tied to the eschewal of grand or meta-narratives: The master subject, the authorial 'I', the knowledge of the intellectual, the idea of one truth, or way of knowing the world, are all called into question. The destabilisation of the binary, between the 'cyclopaedian, self-satiated eye of the master subject' (Haraway, 1988) and the knowledges of previously subjugated others (Foucault, 1980), was another important aspect of this study. From this concern with destabilising the binary construction of meaning, one of the central concerns of this study developed: the

split between non-disabledness as the norm and the experience of disability as Other.

The division of this conclusion into two chapters in which the method receives a separate analysis might be considered inappropriate, given that the binaries between theory and practice have been called into question in this study. However, rather than a reinscription of theory/practice binaries, the reflection on the method, presented in Chapter Eight, should be regarded as an indication of the importance accorded to research practice as an integral part of the theory building process, and the production of local and specific knowledges.

The self-reflexive analysis of the method presented in Chapter Eight brings the study to a point where conclusions can be drawn in light of the completed study in Chapter Nine. The intersections and interruptions between theory and practice implicate both in the production of new knowledges. The new knowledges this study aims to inspire are designed to destabilise practices of Othering and contribute toward future emancipatory politics. Dialogues between feminism and the research participants have contributed toward the production of new knowledges in this study. From the perspective of these knowledges, I conclude this study by wondering what the future might hold for feminism and disability.

Chapter Eight

Methodological Reflexivity: Looking at the Method

Introduction: What Can be Spoken? What Goes Unsaid?

This study was designed to create dialogues between feminism and women with disabilities and destabilise the binaries between non-disabledness as the norm and disability as Other by asking the question of ‘what am I... for her?’. With the hindsight of what I/i¹ now know at the end of this study, the following chapter presents an analysis of the method and methodological issues.

In this study it has been argued that research practices such as the ways in which the interviews are conducted, analysed, and produced all impact upon the research outcomes. Expectations of what the research will produce are also affected by the research practices that are chosen. This study, for example, was not engaged in the pursuit of one, best, or true, dialogue between feminism and disability. The method is a part of the context within which the research findings are produced. In this study, doing research within a qualitative and participatory framework moves the research in particular directions and influences the knowledges that might be produced.

The context within which the research is undertaken performs a boundary setting function, thus influencing what can be spoken and what goes unsaid. It can therefore be argued that the knowledges that a particular study produces can be best understood within the context in which they were produced. A detailed explanation of the context from which information is drawn, therefore refines the reader’s understanding of a text. An explanation of the context within which this study is located (a postmodern, feminist, participatory method) is therefore vital to the reader’s understanding of the text.

It is argued that the method utilised in this study pushes at the boundaries of traditional research strategies². Pushing these boundaries involves writing against conventions that objectify the subjects of research projects and obscure the everyday realities and necessities of the lives of people marginalised by society. In the place of such practices a plan for a method that seeks to involve

¹ Chapter Two provides an analysis of the move to destabilise the authorial ‘I’ and of writing practice in which such (I/i) strategies are employed.

²A discussion of the tension between ‘traditional’ research methods and other ways of doing research methods is provided in Chapter Three.

the research participants and share control of the process of conducting the study is presented. This reflection on the method is intended to move potential future research methods, further along the way towards collaborative and participative strategies.

Aspects of this reflexive analysis of the method have been written in indented paragraphs. The indentation of paragraphs that are not italicised, can be regarded as a discursive practice in which ‘I’ am, in a sense, quoting myself: A double move in which, ‘i’ write myself as ‘I’ in order to destabilise the authorial impulse (that is, ‘I’). This practice can be conceptualised as a process in which I collaborate with *myself*.

The preceding chapters contextualise many aspects of the research. In order to further contextualise this process, this chapter presents a reflexive analysis of this process. The purpose of this reflexivity is to contribute towards future research practices. In the English language reflexive adjectives are not often used. This is not the case in other languages. In Swedish for example, we would say, ‘I feel myself sick’, rather than, ‘I feel sick’. From this perspective, and within the context of this postmodern feminist research practice, a reflexive analysis is my way of saying:

I/i think my-Self the research: Where, this chapter can be regarded as one of postmodernisms’ double moves in which... ‘I’ (the authorial I) reflect on the research in order to illuminate the chinks, gaps, ‘the limits’ of the research. (The spaces where ‘i’ am not ‘I’ and) where change might be possible or desirable, that is ‘the limits’ - of this study.³

To put this another way, this reflexive approach can be regarded as a process of reflection that:

... questions purely rational ways of knowing the world and rebalances them with subjective, intuitive and inductive approaches, thus lending support to new paradigms which integrate theorising, practice and research as part of holistic experience (Fook, 1996:197).

³ See the section entitled ‘writing against conventions that obscure’, later in this chapter, for an explanation of the practice of indenting my reflections on the method.

The reflexive analysis presented in this chapter does this from a perspective that is both postmodern and feminist. I believe that actively standing back from the research can be productive of better theories and better ways of coming to know the world.

In this chapter my reflections on the method are structured in the following way: first, the Life History process is analysed; this is followed by an analysis of the follow-up interviews. Next a reflexive analysis of the process as a whole is offered. This is followed by a discussion of writing practices and the ways in which traditional writing practices can obscure the complexities of the method. This chapter concludes with a discussion of possibilities for future research initiatives.

The Life Histories in Context

The ways in which the Life History method worked to achieve particular outcomes is analysed reflexively in the following section. Topics covered include methodological options, identity issues, collaboration in the interview process, a description of how the principle of sharing control of the interviews worked and participants' feelings about the interviews.

The principle of beginning the research from the experiences of women with disabilities is well established in this study. The Life History process worked as one way in which such an outcome could be achieved. As discussed in Chapter Four, a variety of qualitative methods, designed to solicit the subjective responses of the participants, could have been used to orient the study towards the participants. These options were considered and discarded in favour of the Life History Method. The most difficult of these methods to reject was the group interview.

During the earlier stages of the study I lamented the lack of a group interview. I felt a group interview would stimulate discussion and debate and help to establish some of the more tentative issues raised in the Life Histories. At this stage I realised a group interview was inappropriate because it compromised confidentiality. Later, as the follow-up interviews progressed and an analysis of this Life History material started to develop, it became clear that my reluctance to undertake a group interview had been correct. Privacy and discretion established themselves as vitally important themes. Although it now seems

perfectly obvious that privacy should be important it is a matter of which I had previously been unaware. This retrospective rejection of a group interview offers support for the use of the Life History method as a way of eliciting the subjective experiences of the participants with a minimum of input from the researcher.

The difficulty I had rejecting the idea of a group interview also demonstrates that my embodied difference from the participants is indeed important in the research. If I had a disability and required carers to assist me in my daily routines the research may have begun from the assumption that a group interview was inappropriate and worked around the need for discretion. Attempting to make links between feminism and women with disabilities is not as simple as layering one perspective on top of another.

My understanding(s) of the ways in which feminism and the knowledges of the participants might interact and inform one another have changed subtly over the course of the research in response to my interactions with the participants. The interaction of the theory, the method, and the knowledges of the research participants are implicated in this process. Useful and new interchanges between the two bodies of knowledge have appeared and continue to appear constantly. Caring issues, for example, developed within the context of a Foucauldian analysis of power into a discussion of the ways in which power works in the lives of women with disabilities. Footnote Six in Appendix Two gives some indication as to the origins of this analysis⁴.

The above discussion of the problems inherent in conducting a group interview documents an instance, in this research project, where feminism and disability issues only just stretched to touch one another. For example, feminist sensibilities would suggest the group interview as a productive way to elicit opinions. However, the results of this study suggest that people with disabilities might see a group interview as a further invasion of privacy. In addition, the calling into question of the concept of community in Chapter Seven identifies 'the community' as another site at which disability issues and feminist issues may have passed one another by. Feminism heralds the community as a positive and affirming place, while for people with disabilities 'the community' may be a

⁴ The issue of flexibility was discussed in the context of caring issues and later developed into a discussion and analysis of power. These links between caring and power are continued in the analysis in Chapter Seven.

place they feel excluded from. Bringing a postmodern feminist analysis of communities of selves to the experience of disability is therefore problematic. There may be other instances, of which I am unaware, where feminism and disability issues miss one another completely. What was said, how things were said, and the topics that established themselves were part of a process of negotiating dialogues between myself and the participants and between feminism and women with disabilities. The processes of collaboration and the ways in which the method responds to the needs of the various participants is outlined below.

The Life History interviews produced narrative accounts of the participants' lives. These interviews were written in a collaborative fashion. The interviews were designed to produce stories of the women's lives. This collaborative process involved a variety of strategies, such as: conducting interviews in the participants own space, the use of everyday conversational techniques, negotiating with participants about what would be written into the thesis, space for 'off the record' comments, and returning transcripts to participants for editing. This method was designed to give participants the space to speak on any aspect of their lives they felt passionately about, thus providing me with information with which to make the interviews more relevant to the lives of women with disabilities. This strategy worked effectively. Disability issues were not the only, or even in some cases, the main focus of these interviews. One of the participants wished me to preface her Life History with a disclaimer to the effect that disability is not the focus of her life, rather it was an aspect of her life on which she had been asked for an opinion.

The extract presented below illustrates the process of collaboration and provides an example of a participant speaking out passionately about an aspect of her life not related to disability.

I blame the Catholic church for a lot of problems...no pill... not allowed to get the husband chomped. (vasectomy).

A transcript of the way in which this sentence was constructed paints a different picture.

Stacey: I blame the Catholic church for a lot of problems...no pill...not allowed to get the husband chomped.

Michelle: *Hah, not allowed to get chomped.....I want to quote that bit...shall I write vasectomy?...or is it all right if I write chomped?'*

Stacey: *No write chomped... ..put vasectomy in brackets...'*

The manner in which the interviews were recorded (hand written) also contributed to the final form in particular ways. Kelly was very interested to know whether she could change what she had said. She was pleased that this was the case and asked me if I could put it on disk so that she could use her word processor to change things. At one stage, I asked her to repeat the final part of the sentence she had just spoken, as I hadn't quite managed to get the whole thing down. She asked me to repeat the incomplete sentence back to her twice. The sentence read, '*It was the first time I've felt like I was just like an ordinary person and that I had...[After a moment she completed the sentence]...rights and equal opportunities too and I could get them no matter what*'. After thinking for a moment she said: '*No change it to; was entitled to them no matter what... That sounds far more intellectual doesn't it ?'* (laughing)

Kelly would have been less spontaneous if she felt she couldn't change her words. Being able to reconstruct sentences gave Kelly more control over how she presented herself and how comfortable she felt with the process. Conducting the Life History interviews in a collaborative manner means information is revealed in particular ways. Participants are given control over the ways in which their stories are presented. Encouraging participants to take control in this manner allows the interviews to flow more freely. In terms of creating an environment that fosters participation, the ways in which the Life Histories were collected and constructed functioned well.

The collection and construction of the Life Histories was characterised by variety rather than conformity. This outcome reflects the principle of conducting the Life Histories in a manner appropriate to each participant. Some interviews flowed, some were stilted. Some participants were happy to talk about themselves, others seemed, at least initially, embarrassed. For most people the idea of private interviews and confidentiality inspired disclosure, however, for one participant, Margaret, private interviews were not appropriate. Although the method would suggest that privacy is of paramount importance, in Margaret's interviews, finding and establishing a private time to meet proved to be impractical.

Margaret's interviews were particularly hard to organise. Finding a time when Margaret was home alone proved to be a major problem. As her home help comes in the mornings we scheduled several afternoon appointments. Margaret missed these appointments. I began to think that she no longer wished to be part of the research. However, when I questioned her about it, she indicated that she was very keen and definitely wanted to continue. In the end it became clear that mornings when Margaret's home help was there were the best times as Margaret was likely to be at home. Margaret made it clear that her home help was a close personal friend who was aware of most of the things that went on in her life. Although I feel that the interview process was definitely influenced by the intermittent presence of a third person, Margaret's continued absence at the times in which private interviews were scheduled indicates that she was more comfortable with this arrangement. I feel that Margaret made an invaluable contribution to the project, one which would have been lost had I been utilising a less flexible research method.

Margaret was the most reticent of the participants in the study. During the second interview she requested that I ask questions rather than just prompt her casually as I had done in the first interview. She indicated that she felt uncomfortable just talking randomly. I devised questions from the information she had given me at previous interviews and from a copy of her Curriculum Vitae. Margaret's Life History was constructed in a very different manner from the others in this study, my participation was greater and the topics less 'spontaneous'. The things that remained unsaid in Margaret's interviews, her unwillingness to talk on certain topics and my initial and retrospective responses to this, have enriched the analytical component of this study.

Collecting the life stories of the various women involved in this study necessitated a flexible method. A less flexible method would not have produced such rich dialogues and the stories of one or two of the women would never have been told. Capturing the voices of these more private people is a major strength of the method.

The Follow-Up Interviews

The Interview Guide for the Follow-Up Interviews

When constructing the follow-up interview guide the strategy of looking for issues people felt passionately about, rather than concentrating only on themes

in the Life Histories, worked extremely effectively. Analysing the Life Histories in this manner revealed a variety of issues. Some of these issues developed into themes in the final analysis, some were passed over by the participants and some sparked interest in other issues. The way in which the participants responded to the various questions in the follow-up interviews was revealing in itself. As a process designed to draw comment upon issues people felt passionately about, I feel the strategies utilised in the follow-up interviews worked well.

The follow-up interviews covered both the issues the participants identified as important and my analysis of these issues. My theoretical analysis of the Life Histories began with the construction of the follow-up interview guide. The ways in which I intended to analyse the issues raised in the Life Histories were shared with the participants. In many cases it was difficult to reconceptualise the theory in such a way that it made sense to the participants. However, the mental gymnastics required by this practice helped me to refine my own understanding of the issues. This reconceptualisation of the theoretical analysis also raised the question of how to present the theory in a clear and understandable manner.

The Interviews

The principle of involving the research participants in the research, from the conception to the analysis, is an important component of the method. The Life History interviews allowed the participants to be involved in the conceptualisation of the substantive issues, or issues rooted in the everyday realities of their lives. The follow-up interviews encouraged the participants to continue to develop substantive issues, to share their own theories and analyses and to comment upon my theoretical interpretation of their lives. Taking my analysis back to the participants, so that they have an opportunity to comment and critique, is one of the most innovative components of this study. Margaret's comment, *'I can tell you now I'm definitely not a feminist'*, demonstrates the effectiveness of such a strategy, as does the fact that my analysis of certain issues changed in response to participants' responses in the follow-up interviews.

Analysing the Follow-Up Interviews

Deciding how to analyse the follow-up interviews and carrying this analysis out proved to be one of the more difficult aspects of this study. A method that allowed me to keep sight of the original theoretical categories, while at the same time allowing new themes to develop, was required. The importance of flexibility in the research method was demonstrated in relation to this task.

The initial sorting of the follow-up interview data into the categories of the body, identity and the self influenced the analysis in certain ways. Beginning the analysis of the interviews, by dividing them into these categories served the dual purpose of stimulating close scrutiny of the texts and of providing a visual picture of the ways in which the data did and did not fit the theoretical framework. Sorting the material in this way also revealed the participants differing levels of interest in the various categories. Paying attention to the issues that individual participants felt passionate about facilitated a more productive return to the original interview text. For example, when analysing the relationship between privacy and the body, I was aware that Henrietta and Jane had commented about bodies extensively, their texts, therefore were likely to be fertile ground for further scrutiny. Providing a detailed description of the ways in which information was drawn from the follow-up interviews and an overview of the decision making process leading to this are important aspects of refining the readers understanding of the text. The way in which the analysis of the information, gained in the course of the interviews, is presented, is an aspect of the context from within which the knowledges produced in this study can be understood.

Presenting the Analysis

It was my intention to complete the thesis with the follow-up interview findings and my analysis of the Life Histories presented as a joint analysis. My role and the role of participants' at this point, was to negotiate the meanings that could be constructed from the material from the Life Histories and my theoretical analysis. Dialogues between feminism and disability were actively pursued. However, as I began to analyse the interview data it became apparent that these interviews did not come close to rounding off the original research. Rather, continuing the interview process had stimulated new beginnings. New issues and areas of concern were raised and new analyses of previously discussed issues were offered. The follow-up interviews also revealed the changing viewpoints of the participants. For example, the perspective of one participant had moved from disability activism to a wider arena on a political and personal level, while the analysis of another had moved from radical/socialist feminism to socialist/postmodern feminism. The method was flexible enough to accommodate both the changing requirements of the study and the shifting analyses of the research participants over the course of the study.

A General Reflection on the Method

This study has been significantly influenced by a number of factors yet to be covered in this reflexive analysis of the method. The first of these concerns the overall form of the study. Second, the chronological development of the research methods and the ways in which these methods influence one another and the final outcome of the study are presented. Finally, a discussion of research conventions and some of the more subtle differences between this study and traditional research practices are presented.

Form

Undertaking a series of in-depth interviews, seeing participants repeatedly and dividing the formal part of the research into two distinct phases were extremely successful strategies. Repeat in-depth interviews provided the opportunity for both myself and each of the participants to speak in a less formal, more relaxed manner. Another important factor fostered by this practice is that subsequent interviews provide a forum to talk about any concerns people may have. Providing participants with a transcript of previous interviews and asking for comment creates an environment which is conducive to critical comment. Taking the transcripts back to the participants for scrutiny shows that you have listened carefully to what they have to say and are concerned to represent them in a manner that they feel comfortable with. This is particularly important in this study as most of the participants have been researched, interviewed, quoted incorrectly and not given feed back in the past.

Interactions

Different research methods produce different results. The chronological location of various methods also produces different results. For example, conducting the Life History research alongside the other methods, utilised in this study, could produce different outcomes to those revealed by the present research.

In this study, the Life History interviews provided the starting point for establishing a structure for the follow-up interviews inclusive of the perspective of the research participants. However, many of the themes discussed in the analysis developed autonomously. The participants had well developed analyses of the processes by which disabling discourses are communicated and circulated. The Life History interviews provided an opportunity for the participants to look inwards and talk about their lives while the follow-up

interviews encouraged observations on others' lives, discussions about other peoples' experiences of disability, and about the place non-disabled people occupy in the lives of people with disabilities. The participants were encouraged to share their own analyses of disability issues generally and particularly of the issues specific to the research.

The questions raised in the follow-up interviews directed the nature and content of the analysis in specific ways. Rather than setting boundaries on the topics raised in the follow-up interviews the guide was designed to stimulate further comment and debate. In this respect, the method worked effectively. Information revealed in these interviews followed, supported, subverted, contradicted and moved to areas outside of the information drawn from the Life History interviews.

The postmodern feminist principles grounding this study foster the use of a method that responds to, rather than dictates, the form of the research. In this case the research method needed to expand to incorporate informal conversation outside the original parameters of the research. An important contribution to this study has been made by two of the research participants, Kelly and Henrietta. Both have been part of the process of developing and refining ideas and analyses subsequent to the formal completion of the research process. Kelly's opinions on media representation of people with disabilities and Henrietta's ideas on teaching people with disabilities to train their own carers are a product of the interaction of the method and the participants. These contributions to the study reflect Kelly and Henrietta's personal concerns at particular points in time. They are not a direct product of either the Life History or the follow-up interviews. Nevertheless the methods and the interview techniques are a part of the process that created the environment in which these issues could be shared. The inclusion of Kelly and Henrietta's analyses allows the study to grow and develop outside the boundaries prescribed by the formal research methods.

Writing Against Conventions that Obscure

In terms of formal presentation this thesis adheres to traditional academic conventions. The theoretical sections come before the methodological sections, which in turn precede the analytical sections. These sections are bounded by an introduction and conclusion. To a certain extent this parallels my journey through the theoretical and substantive terrain. However, many factors of the

research are not evident when the research is written in such a way. Writing the thesis in this manner gives no clues to the extent to which the theoretical perspectives change and become refined over time.

Traditional conventions also govern the terms and phrases that are used to describe research. I would argue that although these terms are regarded as neutral and descriptive, they in fact have a major impact upon the kinds of knowledges that are produced. For example, aspects of this study that would be traditionally regarded as empirical are conceived of as *substantive*. Using the word 'substantive' to describe this aspect of the study is a self-conscious strategy designed to establish and revalue the everyday realities of the research participants. This strategy can be conceived of as an aspect of the practice of understanding the research participants as the subjects rather than the objects of the research. Other writing practices used strategically throughout the study and the way in which the study concludes are also testament to a struggle between academic tradition and the postmodern.

The method also conforms to traditional formulae in that it is written in such a way that similar studies could be undertaken. However, care to contextualise the study as the product of a particular historical moment is paramount in the presentation of the method. This practice is important as it marks the study as uniquely the product of a particular time, place and social dynamic. Thus replying to the 'what' component (what in this very precise moment in history) of 'what am I... for her?'. Methodologically, this practice moves the research firmly into the postmodern.

Although the analysis appears as the final stage in the research it was in fact an integral part of the dynamics of the study. Conclusions are drawn but these conclusions also (in one of postmodernisms' doubled moves) leave the research as a beginning, a work in progress, something to be carried on by myself or by others. The following discussion, and the way in which it is written, contextualise some of these issues and practices.

Postmodern feminist sensibilities informed my decision not to undertake a group interview. This decision - that in a more traditional research situation would be merely passed over - provides a good example of the ways in which the traditional presentation of research practices obscure the complexities of the interview process. After a very small number of interviews had been undertaken I/i *intuitively*

knew that undertaking a group interview was not '*the right thing to do*'. I/i *believed* it was important to begin from the knowledges of women with disabilities. I/i *choose* to do this using a Life History method. I/i *wanted* everyone to have a chance to speak before a group interview was conducted. In group interview situations certain ideas, usually the ideas of the most vocal (no matter how carefully the group dynamics are mediated) gain purchase. For these reasons beginning the research process with a group interview was not appropriate. Once I/i realised just how small the disability community - or the part of the disability community with which this study connects me - is, a group interview definitely seemed inappropriate.

Ethical issues informed my *intuitive* decision not to undertake a group interview. I/i can best conceptualise this decision making process as a competition between confidentiality and trust. Compromising the anonymity of the participants by revealing their identities to one another and thus allowing them to assign known or probable personas as the origin of ideas or questions is the most obvious of these factors.

My dilemmas around the issue of trust were less noble and clear cut. I/i *felt* the women would be more reticent in offering thoughts and opinions once they could assign these known or probable personas as the origin of ideas or questions both in the group and in subsequent interviews. Identification, or temporary affiliation with the researcher is a known and encouraged feminist interview strategy (Oakley, 1981, Reinharz, 1984). Having encouraged affiliation through the use of multiple interview techniques, I/i felt that the participants trust in me personally would be broken if they were confronted with the other women involved in the study. I/i had visions of people leaving the study or exercising their right to withdraw their existing contributions. This confusion of half formed thoughts led me to decide against a group interview. Disclosed in another way, these permutations of consciousness could be presented as my considered opinion.

Having revealed all this, my *belief* that a group interview would better achieve the principles of participatory research (despite the fact that for a variety of reasons I/i choose not to utilise this method) makes more sense. In order to gather the information, I/i needed, I/i believed, I/i had to approach the women individually. Once I/i had completed

the Life Histories it seemed unethical to undertake a group interview. A group interview is, I/i think a vital part of a truly participative or collaborative study. A collaborative study involving feminist(s and) women with disabilities would *in my opinion* be productive of exciting and powerful new knowledges.

Even writing this short section against traditional research practice, I/i lay myself open in terms of critiques of the validity of my method. My concern to conduct the research in the *best* way can not be justified with recourse to any overarching justificatory strategy. I have disclosed and worked through the various value bases informing this aspect of the study; the problem now is to legitimate it as scientific knowledge (Lather, 1991).

Future Research Potentials

Creating dialogues between feminism and disability is a foundational principle in this study. Searching in the gaps and spaces between feminism and women with disabilities, in order to find the places where change might be possible or desirable⁵ is suggested as one way in which the aims of this study might be achieved. One strategy designed to create dialogues between postmodern feminist theory and the knowledges of the women with disabilities who took part in this study, was through the use of a participatory method. This participatory method worked well and I believe that a critique of this method has the potential to contribute towards new and better ways of doing participatory research in the future. Now, at the other end of this study, I wonder what kinds of future research might be inspired by a critique of this study. Had I begun a project about feminism and disability after reading this thesis I am sure I would have approached it differently. Research practices and theoretical analysis might have been employed in different ways.

Given the arguments, made in Chapter One, that essentialism can be deployed strategically, and that meanings are attached to our corporeal specificities, I wonder what meanings some-Other-self (or selves), particularly someone with a disability might bring to a study such as this. The following suggestion; that this

⁵ The theoretical background upon which this strategy is founded is discussed in detail in Chapter Two.

study could be analysed by, or in conjunction with a woman with a disability, is forwarded in the spirit of collaboration in which this study was undertaken. Such an analysis might, for example, take the form of a theoretical interrogation of this study designed to bring new meanings to existing research. However, the question of how the validity of such a study might be established needs to be taken into account.

The suggestion, that a further analysis of this study be undertaken by or in conjunction with a woman with a disability, and that such an analysis would be collaborative, moves future research practices outside the boundaries of the traditional realm. Research tends to be conceptualised as an undertaking that passes through a finite number of stages from a definable beginning to definitive conclusion. These ideas have their inception in the positivist traditions of replicable research and expert knowledge. The idea that this study is perhaps still in progress suggests that research can be conceptualised in other ways. Questioning the tradition of research as a finite undertaking, is a deliberate ploy intended to undermine understandings of knowledge as the prerogative of the individualised expert. Collectivised or collaboratively constructed knowledges may have potential to illuminate gaps or spaces, that is, different ways of seeing the world that we may not have witnessed via more traditional research practices and interpretations.

This calling into question of the authority of the author and the idea that knowledge is produced in quantifiable blocks, aims to destabilise the definition of collaboration in collaborative research. Calling the meaning of collaboration into question has the potential to widen the discursive boundaries within which collaborative research is produced. Collaboration can occur at a variety of levels and in a variety of ways within the research process. The research subjects, the researchers, the theory, the research practices and research texts, can all be conceptualised as part of the process of collaboration. Suggesting that this study might provide the substantive foundation for future empirically based enquiry and further analysis, destabilises the binaries between theory and research practice. For example, would a study that began from and utilised existing research findings be conceptualised as empirical or theoretical?

Consideration of two modes of authorship that can be considered to be empirical and theoretical respectively, are discussed in order to answer this question. This analysis calls into question the idea that collaboration must take place within a particular time frame. The following discussion is intended to demonstrate the

potential inherent in widening the boundaries around what is understood as collaborative research.

Empirical authority can be established by people other than those who organise or undertake empirical research. Analysis of a study undertaken before the presentation of a completed document by someone other than the author of the study, or jointly presented material, is unquestionably regarded as empirical. The work of Gibson-Graham, (1994, 1995) - the composite identity of Katherine Gibson and Julie Graham - utilised in this study, demonstrates the acceptability of collaboratively produced research. Gibson-Graham presents an analysis of an empirical research project in which different analytic repertoires are considered. Although it is not clear who undertook the research, who conceptualised the various analytic repertoires, or at what stage this composite identity was constructed, both Gibson and Graham are accorded empirical authority.

If, for example, Gibson had published a critique of Graham's study in which her research findings and Marxist analysis were reconceptualised from a postmodern perspective then Gibson would be accorded theoretical authority. A theoretical critique, such as a literature review, is generally regarded as purely theoretical. However, if the embodied subjectivity of the researcher is taken into account, or privileged in a theoretical analysis, then the research can no longer be regarded as purely theoretical. The lived reality of one person is added to the text. In a sense the researcher intertwines or collaborates with the text. This idea is in keeping with Strathern's (1987) idea of a common text or a dialogue. In this example, widening the understanding of theoretical research practice to include the empirical input of the researcher destabilises the notion of a purely theoretical analysis, thus demonstrating the fragility of systems of classification that define *theory* and *research practice* as antithetical.

The idea of intertextual collaboration could also be stretched to include the interaction between a researcher and an empirical text. In these examples, an analysis previously understood as purely theoretical (such as a literature review), might gain some empirical weight, and empirical research (such as that undertaken in this study) might benefit from further theoretical analysis. These strategies are designed to encourage a movement toward local criticism and the valuation of the knowledges of previously subjugated Others (Foucault, 1980). If knowledges that build upon one another are reified, then, existing research can become a starting point for new ways of coming to know the world.

One way in which a collaborative study might leave itself open to future research is through concluding the study by documenting the participants' responses to the researcher's analysis of their stories. The strategy of refraining from having the last word in a final analysis also fulfils the criteria of involving the participants in all phases of the research project. Although it does not fit with traditional research conventions, this strategy does fit with the principle of privileging the knowledges of the research participants. In order to put such a strategy into practice in a non-exploitive way, the depth of commitment required from the participants would need to be carefully negotiated before the research began.

This study focuses upon the production of qualitative data and is premised upon an understanding that it is necessary to find better ways of doing research: methods that take into account and value the experiences of the people who are the subjects of the research. To achieve these aims a qualitative research methodology was utilised. This process yielded rich and valuable data. However, people with disabilities require quantitative as well as qualitative informative in order to establish their claims. Future quantitative researchers need to carefully consider the ways in which research is framed, the questions that are asked and the conclusions that are drawn. Taking care involves not only ensuring that people with disabilities have the opportunity to speak for themselves, research for themselves and produce their own results, it also requires that tools and resources are available and accessible. As the participants suggested in this study, change needs to be made on every level of the social field, from foundational factors such as non-disabled attitudes and opinions, to practical issues such as educational practices and opportunities. Taking account of people who exist outside of the mainstream is a feature of the society within which we live. In the 1990's, and beyond, the claims of people whom society Others cannot be so easily silenced.

One further suggestion I have to make regards the Pakeha perspective from which this study is presented. In this study I have drawn from analyses of the lives of Maori women, Polynesian women and women of colour. However, as noted in the introduction, this thesis has not tried to present a comprehensive overview of disability issues from a Maori perspective. This is a conscious decision made on the basis that I do not have knowledge in this area. Traditionally a problem such as this would be conceptualised as 'being beyond the scope of this text'. However, in this case:

I/i acknowledge this as a *gap*, *space*, or *elision* in this study. One that needs to be *illuminated*.

The feeling that adding in such an analysis teeters on the brink of the worst kind of politically correct window dressing, plagues me.

The notion of appropriation haunts my thoughts.

Not to mention the question of whether a perfunctory analysis is more or less damaging or racist, than no analysis.

I/i believe that this aspect of the research needs to be undertaken collaboratively.

Which brings me back to the idea of the strategic deployment of identity and a privileging of the embodied subjectivity of people whose realities are different from our own. The challenge inherent in the question of what interpretation some-Other-self (or selves) might bring to this study is intended to stimulate new ways of doing research and producing knowledge.

The suggestions for future research provided in this chapter require a degree of self-reflexivity on the part of the researcher, an ability to stand back from the research and ask *what* is going on *right now* in this study. The final suggestion made in this study, that an analysis of the ways in which reactions, discussions and themes develop can be revealing in itself, also requires that the researcher stand back from the research and critically appraise it. As discussed earlier in this chapter, 'power and the caring dynamic' developed as a particularly interesting issue. Because responses to this issue were very clear, direct questions such as who has the power in the caring relationship could be asked. This prompted further comment and discussions of theoretical concerns to do with power issues in this area. Other areas where the issues were not so clear, or the stories of the other participants were not illustrative of the problem, had to be approached a lot more subtly. The issue of privacy and the ways in which it impacts upon the participants' reluctance to enter into intimate relationships is an issue which developed in more subtle ways. One way in which my interpretations of the privacy and sexuality theme could be presented, is offered below:

Reading Between the Lines of the Participants Stories: I come to the following understandings. The future is uncertain. Your disability might get worse. Your life and the choices you make are constantly scrutinised in multiple ways. If you have a partner, your partner is a Saint and you are their burden; they have to care for you. You live in

a society where caring is not a high status job. So many people are involved in your life that you have no privacy. Would you choose to let someone else get intimately involved in your life? What needs to change?

These understandings and interpretations read through the theoretical perspectives utilised in this study suggest that the discursive construction of disability maintains relations of marginalisation for women with disabilities. This marginalisation is maintained through binary divisions that situate being non-disabled as hegemonic and, thus, powerful and having a disability as Other. Relations of power existing throughout society can be deconstructed through an analysis of the ways in which disability is constructed. In this study deconstructing the real and imagined conversations we have with our(s)Selves and (o)Others might provide unthought of insights into the ways in which marginalisations are maintained.

Conclusion

I consider this study to be part of the process of exploring alternative methodologies through feminist research practices. As this study demonstrates, feminism's openness to alternative methodologies holds potential for disability research and politics. The feminist principles upon which this study is grounded require that the research process is presented in such a way that it opens itself up to critique. The reflexive analysis of the research practices utilised in this study provides a starting point for a process of critique.

As a study located in a particular postmodern moment I feel this study achieved its aims. The intersection of the theory and the research practice in the use of a qualitative, participatory, postmodern, feminist method interrupts the discourses of feminism and disability in particular politically desirable ways. The following chapter, Chapter Nine, moves this analysis into the wider 'public' realm with the question of intersecting the interruptions between this study and social policy initiatives. Chapter Nine also considers the idea of Othering and the variety of ways in which people with disabilities are Othered in non-disabled culture.

Chapter Nine

**Intersecting the Interruptions: Theory and
Policy and Identity and the Body and the
Self... ‘What am I... for her... now?’**

Introduction

This thesis is structured around the practice of creating dialogues between feminism and disability. This is achieved by foregrounding the question of ‘what am I... for her’, and interrupting the discourses that produce disabledness as, Other than, and, inferior to, non-disabledness. This chapter considers the original research question of the productive opportunities opened through interactions between feminism and the women with disabilities who participated in this study, in terms of the outcomes of this research as it relates to achieving politically desirable goals. The issues such an analysis generates, are discussed in terms of their relationship to social policy outcomes.

Theoretical analyses vis-a-vis, identity, the body, and the self and factors stemming from the embodied subjectivity of the participants merge to produce a text peculiar to this particular postmodern moment. Written through a framework of feminist postmodernism this final chapter draws together the analyses of identity, the body and the self presented in the previous chapters, asking, ‘what am I ... for her... now?’, here, at the other end of this study. The issues, theories and insights arising over the course of the study are drawn together in a discussion of their relationship to social policy initiatives. This chapter concludes with a discussion of Othering. This discussion of the processes of Othering leads to the question of what the future holds for feminism and disability. The final journey undertaken in this study begins, below, with the body.

Writing the Research into Social Policy

Caring and Selves, Written Through the Body and Into Policy

Social policy is conventionally conceived of as ‘...concerned with the mainly governmental institutions and arrangements for promoting social welfare through the amelioration of social and individual needs as socially defined’ (Hewitt, 1991:239). The place social policy plays in the maintenance of the autonomous individual needs to be taken into account. Within the context of applying theoretical constructs to the everyday caring needs of the participants in this study, the question of how the politics such strategies engender is

translated into terms commensurable with social policies, remains. Hewitt (1991:225-226) suggests that:

Social Policy plays a coordinating role in forming 'the social'. It promotes and organises knowledge, norms and social practices to regulate the quality of life of the population, its health, security and stability. For such stage craft Foucault and others employ the terms 'the politics of life' and 'bio-politics'... It is Foucault's contention that the body, individual and collective, becomes the raw material for this undertaking.

In this study, social policy can be clearly seen to be working at the site of the body.

In a sense, this thesis is written through the body. If bodies were not important this study would have been written differently. Non-disabled people's assumptions about and responses to people with disabilities, understood as culturally specific responses to the physical manifestations of disability and the links between privacy and sexuality, established themselves as major issues in this study. The modes of resistance the participants employ to mediate these factors are analysed alongside their critiques of disabling practices. The problems encountered by the women in this study are not regarded as fixed and immobile. Attitudes and expectations can change and guidelines to manage privacy can be established. The issues that affect sexuality and intimacy can be mediated in various ways.

The tyranny of the notion of the autonomous individual is argued against in both feminist and disability texts. In Chapter Two this concept is discussed in terms of philosophical arguments around the death of the subject and the question of the agency of the individual. A variety of strategies by which it might be possible to move past the notion of the unified universalised self are presented in this study.

It can be argued that looking at the notion of the autonomous individual through the lens of the research participants makes it possible to understand how autonomy might be constructed differently. Non-disabled people might define autonomy in terms of physical independence, while people who require full time

carers might understand autonomy as having control over the who, what, where and when of caring.

An understanding of the ways in which caring requirements are discursively created can be proposed. The current Purchaser/Provider model adopted by the Government for the provision of health and disability services (Upton, 1991) demands specificity in contractual arrangements with well defined outputs. This approach however, may focus attention away from the person with a disability, requiring the care. In the current Funding Agreement¹ with Regional Health Authorities (RHAs) the Government has defined separately household management services from personal care services. It can be argued that defining these services separately has little relevance to the issue of personal autonomy at the level of the person requiring the care.

In order to address issues that are difficult to define (such as the issue of personal autonomy) indicators such as quality assurance are utilised in the formulation of policies such as Funding Agreements. Quality assurance is designed to ensure that as many contingencies as possible are covered in the planning stages of policy development, through processes of consultation and peer review. This type of contractual accountability is relatively easy to measure. The service is either being delivered to a particular measurable standard or it is not. However, the fact that a service is being delivered does not mean that the overall well-being of a person with a disability has been met.

It can be argued that the question of who is consulted and on what basis these people are chosen, needs to be carefully considered if the principles of quality assurance are to be fully implemented. If the policies are designed to foster accountability, and this is their primary focus, then consultation processes are unlikely to be designed to assure the quality of the service to the end user. The accuracy of accountability procedures become the prime focus and the material needs of the end users become secondary.

In response to these ideas, Joe Manning² suggested that consultation is both an important quality assurance mechanism, and an effective means of minimising

¹ 1996/97 Funding Agreement between the Crown and RHAs, S4.9.1, p. 97.

² Manning, Joe (Relationship Manager, Performance Management Unit) (31, January, 1997). Meeting about social policy initiatives as they relate to the care requirements of people with disabilities. Ministry of Health, PO Box 5013, Wellington New Zealand.

the risk of policy failure. But that risk can never be eliminated. There are always a range of variables that affect the quality of the policy development process. Policy, for example, may be dependent on the model of policy development chosen. Current policy advice to Government relies heavily on rational policy development using economic frameworks. He also suggested that, the quality of policy development, like any other task, is dependent on the level of resources available. Inevitably trade offs have to be made and all options may not be able to be reviewed to a rigorous conclusion.

In terms of the discussion of autonomy above, it can be argued that despite intentions of providing a quality service, using economic frameworks to develop social policy means that the who, what, where, and when, of caring needs, become further removed from the control of the person requiring care. Thus power (in this case institutionalised policy frameworks) can be seen to be working through the body (via the regulation of caring provisions) to achieve material ends. As discussed elsewhere in this thesis, power, in a Foucauldian analysis is understood as a relation. These relationships of power are 'changeable relations' that require '...on both sides at least a certain form of liberty' (Foucault, 1988b:12). Discourses exist within relations of power which take specific forms in particular societies:

The field of force relations includes social institutions, which are the site of discursive conflict over how subjectivities and social relations should be constituted and social control organised. This conflict has important implications for the ways in which individuals are constituted and governed as subjects. Not all discourses have the social power and authority which comes from a secure institutional location (Weedon, 1987).

The discussion of caring needs demonstrates an interaction between a powerful institutional discourse of accountability and a resistant discourse of an alternative conceptualisation of autonomy. I have found that aspects of the research on which there is a tendency for agreement are the more publicly debated and considered issues, often ideas that have been realised at a policy level. While more private issues, such as those around sexuality, tended to elicit more diverse responses. Although this result is far from surprising, it does illustrate the normalising function of widely circulating discourses. However, widely circulating discourse also tended to attract more derision: 'Where there is power, there is resistance' (Foucault, 1978:95) and I have seen the participants'

resistance to the current understandings of care and care provisions in a variety of settings over the course of this study, from grumblings about carers, to erudite argument with the manager of Disability Support Services (Ministry of Health).

What I/i See, in Social Policy Beyond Simple Deployments of Identity

It has been argued in this thesis that people with disabilities experience marginalisation on the basis of their embodied identities. Nevertheless, discourses of identity can be seen to be working to achieve positive outcomes for people with disabilities. The ways in which the discourses around disability have changed in Aotearoa/New Zealand's recent history can be demonstrated with regard to the legal and moral imperatives used to justify the demands of people with disabilities. For example, the Human Rights Commission Act 1977 did not cover people with disabilities. In 1990 the Human Rights Amendment Bill proposed ten new grounds for relief from discrimination, disability was not included. Margaret Mulgan, the then Chief Human Rights Commissioner, believed that disability should be included as a grounds for relief from discrimination, but, indicated that in order to achieve this she would need more staff (in Dickson, 1991). The current Act now covers people with disabilities.

Despite the critique of identity as a political construct, advanced in this study, it cannot be denied that identity is being used to achieve positive ends for people with disabilities. The critique of the experiences of colonisation and marginalisation that people with disabilities experience led me to approach the current study in a particular way. The politics of identity also provides important background for the discussion of the ways in which the self is constructed in relation to the Other, and the consequences of the practices used to maintain distinctions between self and Other; that is, the practices of Othering.

Chapter One presents an analysis of the concept of identity. The notion of identity, as a concept that contributes towards the maintenance of having a disability as Other than and inferior to not having a disability, is called into question. This analysis of the place of identity, in the maintenance of disability as Other, is also analysed at the sites of the body and the self. In the section below, a discussion of Othering, as a construct which has impacted upon the entire study, is presented. Discussions of the practices and processes of Othering can be found throughout this thesis. The analysis presented below draws these

various strands together. Theoretical considerations and the ways in which the concept of Othering can be related to social policy initiatives are considered.

OTHERING

The methodological parameters of this study are intended to guard against appropriation of the Other. This research began from a perspective that privileged the principle of conducting the research in a manner that would avoid appropriation of the voices of the research participants, thus mediating its own part in the processes of Othering. The ways in which research methods work to Other the subjects of research are discussed in Chapter Three. Some degree of appropriation of the Other cannot be avoided in a study which is not 100 percent collaborative. However, an evaluation of the emancipatory potential of the method must take into account the potential the research has to highlight and problematise the discursive practices operating to Other women with disabilities. The relationship between woman as discursively constructed Other and woman as the subject of their collective histories is one of the central questions feminism seeks to address (Mohanty, 1989). Mohanty suggests that the connection between women as historical subjects and the re-presentation of women as produced by hegemonic discourses is an arbitrary relation, set up by particular cultures. Methodologically and theoretically this study's design problematises this arbitrary re-presentation of women with disabilities. The previous analytical chapters reveal some of the numerous ways in which women with disabilities are discursively constructed as 'the Other'. The following discussion draws these analyses together and develops them in terms of their political potentials.

A theoretical examination of Othering is presented as the concluding section of this analysis precisely because the themes involved in the processes of Othering are so numerous in this study. Normalising discourses working throughout the cultural milieu of Aotearoa/New Zealand serve to re-present women with disabilities in particular ways. Heterogeneity is subsumed to a discourse of the singular knowable subject - 'woman with a disability'³. In this study this known and knowable subject becomes the knowing subject. The Other reinscribes itself

³ One of the women in this study labelled herself 'This city's disabled woman', as at one point in her life she felt the media actively searched for excuses to include her in stories to which she considered herself a peripheral player.

in multiple, diverse and ephemeral ways. Thus, the practices of Othering become more difficult as the Other becomes more difficult to define.

Writings against Othering comprise a significant component of this thesis. This writing against Othering involves exposing and problematising practices that reinscribe or normalise practices involved in Othering. The logic of the same; the logic of what we know and understand as normal; the logic of things that are taken for granted and never considered. This logic is part of the process that maintains relations of marginalisation and privilege in our society. This way of knowing the world is involved in practices of Othering. The theory; the method; the methodology; the people involved with the study; the interview process; the writing up are all involved in this critique. Knowledges and practices of Othering specific to this particular study are analysed in the preceding chapters. The ways in which Othering works in relation to the lives of the participants in this study are illustrated via a discussion of the participants' views of non-disabled peoples' responses to and assumptions about people with disabilities.

Non-disabledness is popularly regarded as the norm, having a disability therefore becomes Other than and inferior to the norm. This study examines an aspect of Othering related to personal relationships. The stories of the participants suggest that the processes involved in Othering function to negate equality in relationships between non-disabled people and people with disabilities. In addition, the discourses surrounding masculinity and femininity function to produce gender specific subject positions for non-disabled people in their relationships with people with disabilities. That is non-disabled men's and non-disabled women's choices to be in a relationship with a person with a disability are constructed differently in non-disabled society. A man is regarded as a knowing subject, aware, in control of the situation and worthy of praise. A woman on the Other hand, is not accorded the same level of respect. Gender functions to structure the discursive spaces within which relationships between non-disabled people and people with disabilities exist. Women and disability are both accorded the status of the Other.

Other examples of the outcomes of the practices of Othering arose in the course of this study. The processes involved in the practices of Othering are apparent in non-disabled peoples' responses to easily identifiable manifestations of disability. The ambivalence expressed in participants' discussions of their attitudes to, and uses of their wheelchairs, provides another example. The non-disabled cliché 'confined to a wheelchair' is called into question. For the

participants, wheelchairs are anything but confining. The participants talked at length about the benefits using a wheelchair had brought to their lives. However, this does not negate the very tangible ways in which such negative discourses affect the lives of people who use wheelchairs.

The ways in which I, as the researcher, participate in these processes of Othering is a necessary part of this discussion. This study was designed to elicit challenges, discussion and contention. The method was successful in that the participants challenged me on many different occasions. These challenges have effected numerous changes over the course of the study. The most difficult part of this practice involved opening myself to critique of my analysis of the situation. Two comments made in the follow-up interviews facilitate the following discussion. Both concern resistance to practices of signification. The first of these is related to my practice of talking of women with disabilities when a participant considered that the situation was relevant to all people with disabilities:

Michelle: [...] people are cynical about the changes to building regulations saying they're more about satisfying codes than making changes for women with disabilities.

The second, critiques the practice of speaking of people when I clearly was talking of non-disabled people:

Stacey: I think you're talking about people with disabilities.

In the previous chapter Margaret commented that she was definitely not a feminist and that women did not need to be singled out from people with disabilities. Stacey's comments on the Other hand, are not against feminism, or a feminist analysis of the research; however, she is also suggesting that problems are applicable to a wider range of people than women with disabilities:

Michelle: People said that other peoples' expectations of what people with disabilities can do is a major source of frustration.

Jane: I think probably they are talking a lot about an ablebodied person and not another person with a disability.

Jane's comments reinforce the theoretical ideals of the study. That is, that if I am speaking of non-disabled people, I should state that I am speaking of non-

disabled people. If I fail to state this, I am reinscribing the discourses of non-disabled person as norm, person with a disability as Other. This analysis points to the need to pay attention to the micro processes of power such as speech practices as a vital component of political strategies.

The way in which the processes of Othering work to produce certain choices and options can be seen in relation to other aspects of this thesis. On a practical level, the participants critiqued caring provisions throughout the course of the study. Choices of carers, from the original use of Nurse Maude to the current RHA funded Homecare 2000, have seldom been considered adequate. The changing age structure of the population in Aotearoa/New Zealand towards a proportionally larger older population together with advances in technology, suggest that regarding disability as Other than the norm is going to become more difficult in the future. At the 18th World Congress of Rehabilitation, '2000 And Beyond' Len Cooke, of Statistics New Zealand, suggested that we will see an increase in the size of the population with disabilities. This includes increases in the numbers of women, older people and people from ethnic minorities with disabilities. Alongside this we will see increased numbers of people with severe or multiple disabilities. Such changes necessitate provision for increased demand for support services and attention to regional dimensions of disability.

These statistical forecasts necessitate greater awareness of, the realities of and consequent support, for people with disabilities. Enabling people to be active participants in Aotearoa/ New Zealand's economic and cultural future should be the primary factor in policy provision. If we could no longer relegate disability to the negative pole of the disability - non-disabled continuum then issues, such as providing adequate carers (so that people can achieve all they need to in a day, rather than becoming bogged down in the time consuming and stressful business of managing and maintaining care provision) would take precedence over the current focus on short term cost cutting measures. As Lester Mundell suggested at the same session of the Rehabilitation International conference, 'too often we lose sight of the people in the drive to tighten budgets'⁴. The hegemonic discourses of budget cutting and accountability that currently structure health care funding contribute to the processes of Othering in their

⁴ This sentiment was reiterated in a subsequent conversation. Mundell, Lester (3 December 1996). Personal Communication. Social Welfare, Social Policy Agency. Wellington, New Zealand

constant attention to minimum input. Minimising inputs currently takes precedence over focusing upon outcomes such as maximising quality of life. The discursive production of disability in Aotearoa/New Zealand needs to be challenged in multiple ways on every level of the social field. In this study it has been argued that challenges to practices of Othering have the potential to contribute toward making the future a more hospitable place in which to live life with a disability.

I wonder what the future holds for feminism and disability?

Some of this wondering, in terms of future research potentials and policy initiatives, has already been written in the course of these final chapters (Chapter Eight and Chapter Nine). However, in postmodern fashion, I wish to end this thesis with a self reflexive return to traditional scholarship. The traditional scholar took from a variety of sources and meshed these ideas into a meaningful whole. Billig (1988) suggests that the traditional scholar read as widely as possible, taking ideas from a variety of sources. From this perspective, hunches and individual quirkiness are very much a part of traditional scholarship. Traditional scholarship, then informs this study. However, bringing a postmodern perspective to the idea of traditional scholarship suggests that we should acknowledge and examine the sources of our ideas. Throughout this project when I read something that inspired me I collected it in a specially marked file. A diverse range of material, including feminist theory and literature, philosophical writings, postcards and newspaper clippings are included in this file. In this file, traditional scholarship, passionate scholarship (Du Bois, 1983), an excerpt about Descartes on 'wonder' as the first passion, and Warner's (1995) excerpt on wondering taken from her book entitled 'From the Beast to the Blonde', mingle. These ideas taken in the context of the feminist postmodern ideas inform the concluding section of this thesis.

What might *passion*, *scholarship*, and *wonder* produce. For Descartes the first passion was wonder. This passion is not opposed to, or in conflict with anything else and exists always as though for the first time. When our first encounter with some object surprises us, and we find it novel or very different from what we previously knew, or from what we supposed it ought to be, this causes us to wonder and to be astonished at it. It has no opposite, for if the object before us

has no characteristics that surprise us, we are not moved by it at all, and we consider it without passion.

Returning to Foucault's analysis of working at the limits of ourselves makes me wonder what the future might hold for feminism and disability politics. This thesis ends with an excerpt from Warner's (1995:xvi) analysis of the fairy tale.

'The verb 'to wonder' communicates the receptive state of marvelling as well as the active desire to know, to inquire, and as such it defines very well at least two characteristics of the traditional fairy tale: pleasure in the fantastic, curiosity about the real. The dimension of wonder creates a huge theatre of possibility in the stories: anything can happen. This very boundlessness serves the moral purpose of the tales, which is precisely to teach where boundaries lie. The dreaming gives pleasure in its own right, but it also presents a practical dimension to the imagination, an aspect of the faculty of thought, and can unlock public and social possibilities'.

In a fairy tale everything is constructed and anything might happen. That a fairy tale is a construction, is not disputed. What might happen as we begin to read a fairy tale takes us to the limits of our own imaginations. Telling the tale we create the moral boundaries of the tale. I am sure that the future of the tale of feminism and disability lies outside the moral boundaries of the present tale. But I/i wonder where, outside the boundaries of the present tale, the future tale lies.

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Appendix One:

Access Documents

Information Sheet

Name of Researcher:

Michelle Lunn

Name of Participant:

What Your Participation in this Project Entails:

I wish to conduct six two hour interviews in which you talk about your life experiences. These 'Life History' interviews will be followed up by a group and/or individual interview in which the themes which have emerged from the research will be discussed. My purpose in conducting this second set of interviews is to ensure that I have identified information that is important to you. A copy of the agenda for the group meeting or the additional individual interview will be sent to you prior to the date of this meeting so that you have time to think about what you would like to say. Your participation in the group meeting is optional. If you do not wish to attend I will visit you to discuss the agenda for the meeting. I would also like your opinion the topics which were discussed and my analysis of this. You can attend the meeting and also talk to me in private.

You are free to question me about the research at any time during the interviews. The interviews will be held at a time and place of your choosing. You are free to change the time or place of the interviews at any time.

There is a possibility that the research process you are agreeing to be part of may give rise to recollections of past experiences which may cause emotional distress. At any time you may discontinue an interview or postpone it until another time.

A typed copy of the transcript of previous interviews will be provided to you before the next session so that any alterations can be made. A finished draft of the final Life History will also be provided. You will be provided with a copy of your completed Life History.

Confidentiality

Original information will be seen only by Michelle Lunn.

All original transcripts and tapes will be kept in a locked cabinet in my home and will not be released to anyone.

Names, places and other distinguishing characteristics will be changed to preserve confidentiality.

Michelle Lunn has the right to use information gained in this research project to complete her PhD and produce any further published or unpublished papers. Copies of papers will be provided to you on request.

Consent Form

I agree to participate in the 'Life History' research and the subsequent group and/or individual interviews as described in the information sheet. I have read the information sheet and had the research process explained.

I understand that any features or characteristics which could identify me will be removed from the research results.

I understand that I retain the right to delete any material I do not wish to have associated with my fictitious name.

I understand that I may refuse to answer any question at any time.

I may at any time withdraw from the research.

Name of Participant:

Signature of Participant:

Name of Researcher:

Signature of Researcher:

Date:

Appendix 2

The interview guide for the second set of interviews is provided in this appendix.

The issues raised over the course of the Life History interviews provided the basis for this interview guide. The italicised texts represent the ideas of the participants. These texts were drawn directly from the completed Life History interview transcripts.

The footnotes in this section were originally included in the interview guide to provide me with prompts for discussing the theories I was intending to use to analyse the issues that had been raised in the Life History interviews. These notes will for the most part be unintelligible. However, they give some indication of the kind of theoretical issues raised in the follow-up interviews.

Agenda of the Second Set of Interviews¹

[1] You become your disability.

...Bodies become fragmented what's wrong becomes the focus rather than the person as a whole'. [Morag]

[2] Having a disability is identified as a major defining feature in people's lives. However, an identity as a women is also strongly claimed.

A major problem for Morag at the moment is losing sight of herself because of what is happening around her. 'As women irrespective of what is happening in our lives we lose sight of our own beings'. ²

[3] Sexuality tends to become at once taboo and the subject of public scrutiny.

Question time was another interesting feature of the school visits. 'The little kids asked questions like how do you go to the toilet and dress yourself. The bigger kids ask "can you have sex?" at which point the teacher leaves the room'. Kelly told them, 'Yes my frustration is the same as yours... yes I have sex... I'd speak in their lingo.....yes. I can have a bonk if I want to. It's not that difficult I do want to have kids one day'. [Kelly]

Morag spoke of not getting straight answers from the Doctor about sex because sexuality is seen through the lens of disability

'I asked [the doctor at the rehabilitation unit], "What about sex?." It's not considered nice for people with disabilities to think about these things. Good grief, what a disgrace!. He was

¹ The footnotes, at the bottom of each page are my notes for an explanation of the theory .

² Address Lorde

shocked. Afterwards he came back and talked about it. But what he said wasn't useful'.³

[4] The situation for women with disabilities is different from that of men.

Unless a partner can care for you... finding someone to care for you is harder if you are a woman because men are not socialised as carers.

Societal attitudes are responsible for the fact that women and men have different experiences of disability. From her discussions with a group of women with disabilities Henrietta discovered that often if a woman's partner is a man without a disability people will say, 'Oh, he's so good for her. Nobody ever thinks about what women with disabilities have to put up from their partners'. [Henrietta]

Relationships

...The whole thing about relationships is more acceptable for young men. Young women are more attracted to men with disabilities than young men are to women with disabilities, probably because women are brought up to perform a caregiving role.

³ Foucault, power knowledge working in particular ways. panoptican

303a, 133, 303. A Foucauldian analysis of this would suggest that people are subjected to technologies or modalities of power. These technologies of power operate to define peoples lives. I would suggest that power is at work in two major ways in these examples.

First the most obvious way in which power is operating in this example is through social scrutiny. Foucault refers to this as the panoptican. (explain what panoptican is). Peoples questions about sexuality serve as a form of social control. Why don't some of the participants want people to know the intimate parts of their lives? Not coming home early in the morning. Not wanting to have a relationship?...Privacy issues.

The second example highlights an issue documented in the literature on women and disability. That is, that making information on sexuality available for women with disabilities is not considered important. Doctors do not share or do not have personal knowledge and there seems to be very little research or other information available for women. (Apart from Jenny Morris...) I think this is an area that women with disabilities should investigate for themselves.

Physical needs

...The experience of women with disabilities is different than for men with disabilities. Starting from the basic level of physical needs things are different. When interviewing caregivers questions to do with menstruation are particularly important. At [the institution] tampons were regarded as dirty. However, Henrietta doesn't think they would have thought twice about inserting suppositories.

Henrietta talks of 'an extra dimension of awareness' women with disabilities need to have. Henrietta finds it difficult to have male caregivers. This was a particular problem [in the residential setting] where they told Henrietta she was, difficult, arrogant, and sexist. All the arguments feminists had developed were thrown back at Henrietta by the institution. The only concession they made to Henrietta was that she didn't have to have male caregivers if she had her period.

Education

... Educational opportunities are different for women with disabilities than for men. Women don't have the same educational opportunities as men. If you are a woman your educational expectations and others expectations of you are lower. The same is true of career choices and expectations.

Social Expectations

Societal attitudes are responsible for the fact that women and men have different experiences of disability'. [Henrietta]

Morag has given herself permission to be more vocal. She is no longer prepared to sit on the back bench and watch women and women with disabilities being sideswiped and put on the back burner.

[5] Privacy is a major issue.

Morag

Total strangers asking intimate questions, is another intrusion Morag has to deal with. Getting answers to her own intimate questions is equally problematic.

Rather than regular check ups with the GP Morag has a contract with the Doctor to say she will only visit when she has a problem. This means that the doctor knows something is wrong. If Morag visits she is there for a reason. She rarely sees the Doctor and he respects her wishes. Changes to the privacy legislation have prompted Morag to keep her medical files herself. 'I feel strongly about privacy issues and client confidentiality' ⁴

In terms of not having the opportunity to have a private relationship...

Privacy is a big issue for [this participant]. 'You have very little privacy'. There have been times in [the participant's] life when she has been interested in pursuing relationships with men but the logistics of doing this have put her off. 'If you have a carer to put you to bed and get you up you have very little privacy'. [The participant] sees her options very clearly. 'If you have relationships you have to find a way to move around (caregiving needs) or you don't have a relationship at all... You have very little privacy from the people involved in your life because the people are there all the time... The things I find personally very difficult is toileting... bathing, dressing... stripping off naked in front of other people. You have no privacy... After a time you shut off, but it's always there'.

Having no right to privacy in institutional and/or residential settings.⁵

⁴ 90,91,301 Having a disability may enable an extra dimension of awareness. ...Have a slightly different perspective on the social construction of femininity. Are discursively constructed in different ways. resistant discourse.

⁵ panoptican

Henrietta finished her degree while she was living [in the residential setting]. 'Living [in the residential setting] was a good stepping stone, but it was actually worse than [the institution] in a lot of ways. The caregivers were untrained and slack. They had no respect for people's rights and privacy'.

Lack of privacy because of physical dependence on other people

If Henrietta had to pick one thing which she felt defined her life, it would be her physical dependence on other people. The fact of having to work out who will look after Henrietta and when, takes away a lot of the spontaneity and privacy from Henrietta's life. 'The parameters of your life become quite defined...'

[6] Flexibility

'The idea of attendant care is brilliant; it took people with disabilities a long time to set up and get running'. Although attendant care gives more flexibility than the district nurses, Jane pointed out that it is a job for the carers and you can't expect them to be particularly flexible about the hours they work.⁶

Henrietta also talks about this.....

'... you can't just ring up your caregiver and say come later'. The lack of spontaneity is not something which is easily resolved. A lot of juggling goes on in Henrietta's life. The recently acquired car has made a difference but carers still have to be organised.

⁶ 503. The involvement of people with disabilities in issues such as attendant care and the recent human rights act are acts of resistance under Foucauldian analysis. As would the many ways in which people with disabilities mediate the need for greater flexibility in their lives.

[7] The trade off between security and flexibility: Having someone in your home or in your life constantly, can be experienced as a major infringement of both privacy and security.

Having MS makes it necessary to have home help in order to manage daily tasks. 'It's not a choice to have home help it's an energy based thing. But there is also a trust factor having people coming into your home'. Morag describes her home help as 'superb'. She has heard lots of 'horror stories' from other people though.

For people who need help for day to day personal tasks the number of people who have keys to the house is an important factor.

Irrespective of the nature of the relationship Henrietta may have with her carers, the caring relationship has to be constantly re-negotiated and boundaries need to be set. When there's 'more than six keys out' this indicates that things are getting out of hand. More than six keys means more than six carers. Five is the optimum number of carers as it gives everyone a reasonable amount of work while still allowing some flexibility. 'Sometimes it's stressful... if you get a high turn over'.

Having a greater number of carers can be viewed positively. Stacey viewed it as a situation which gave her greater control over her life.

At present Kelly has six carers. She would prefer to have three, but doesn't have much choice as no-one wants to work so many hours. Having a greater number of carers works in Kelly's favour to some degree, as it means she has more options when it comes to hiring and firing.

[8] Other people's, expectations of what people with disabilities are capable of doing can be a major source of frustration for women with disabilities.

'...but MS is always difficult; its always different. I walked up the stairs and back down again, it took a long time but I did it.

The physio yelled at me to get down off the stairs and back in my chair... I liked the pool. When I first went to the pool I had a tyre... The physio would flip her lid if I got out of the tyre. I had to get out of the tyre when she wasn't looking'. The physiotherapist seemed to think Stacey was going to 'drown or something'. In the end Stacey was swimming lengths. 'Twenty minutes is the longest you are allowed in the pool, its not always long enough...' Health professionals attitudes to what people with MS can and cannot do is a major source of frustration for Stacey.

[9] Accessibility

Changes to building regulations and the provision of more disability car parks make life more pleasant for women with disabilities however these changes have been greeted with a certain amount of cynicism.

'I don't care if nothing else is accessible I need an accessible loo... I do really care - but a lot of people can get up out of their chair to go to the loo but I can't. If new buildings are being constructed they need to consult with people with disabilities about how... I feel that's the way they should go if they've never come across people with disabilities before'. Margaret's general opinion on buildings that have been built lately is that they look from the outside as if they've catered for people with mobility impairments but when you get inside it's a different story. 'They build a building and it has one ramp into the front of the building and the rest of the building has no stairs and no toilets. Places have to be accessible inside as well as out. I think they're getting better. I've been in buildings and outside is spacious and has a ramp...inside you can't move for the furniture... some doctors' offices are like , that...'

The [tertiary institution] seems to be more open to making changes for people with physical disabilities than it is to making changes with regard to women and Maori. Henrietta attributes this to the fact that the provision of a door, for

example, is a tangible, one off occurrence. They can sit back, pat themselves on the back and say look at what we've done.⁷

'...I was invited to a wedding on January the eighth... I was thinking shit... Straight away all the don'ts hit me... I don't want to miss it'. But access problems and the lack of toilet facilities may mean that Stacey is not able to go the wedding.

Even going into town can be a pain. Getting into shops can be tricky and 'if sections of pavement are broken you can't wheel yourself along them because you might fall into the gutter. If it's raining you can forget it... no way'. (Stacey)

Accessibility problems have limited educational opportunities.

Accessibility problems combined with the fact that the secondary school teachers didn't consider it to be their job to help somebody to the toilet, meant there weren't many options available to Henrietta.

'There's a lot of things out there but the schools are inaccessible...' [Margaret]

Access courses are often run in buildings where accessibility is a problem. [Margaret]

Margaret has obtained the course information relevant to psychology, however, many questions remain unanswered. Is it better to study internally or externally? Will the campus be accessible enough?

⁷ 67, Foucault would suggest that there are much more subtle forces working to produce the current social order than those considered acceptable in the past. However, he would argue that present technologies of power are just as prescriptive as those practiced in the past. Foucault's example, it is no longer acceptable to publicly flog someone. It is also no longer acceptable to be openly racist but people still hold racist attitudes. It is not acceptable to discriminate against people with disabilities any more. An easy and public way to do this is to change physical surroundings.

Attending a mainstream secondary school was not an option because the transport system was inadequate and schools were inaccessible.

[10] The experience of women with disabilities is different from the experience of men with disabilities.

The experience of women with disabilities is different than for men with disabilities. Starting from the basic level of physical needs things are different.

[11] Personal relationships for people who have been diagnosed as having a disability become problematic over time. Family members don't know how to handle the disability so they withdraw.

Things have gone from bad to worse with the family. It doesn't worry Stacey as much now as it used to 'but it will-always'. In the beginning, when Stacey was first diagnosed with MS, her mother 'made out that we were all in it together, and we'll all see you through. But things really started going down hill when I was diagnosed'.⁸

Morag's husband was a 'walking paraplegic'. 'He didn't cope with the diagnosis of MS. Morag was supposed to be the caregiver, not him! The marriage lasted three years and two days. It ended soon after he called the general practitioner to ask how long it would be before Morag would be put in a rest-home. 'I couldn't spend the rest of my life with a man who felt this way about me!'⁹

⁸ people being ignorant about the lives of people with disabilities ...scared of it...maintenance of oppressive social structure which doesn't care for people who are other
468, The silence surrounding disability and peoples consequent ignorance makes people frightened of disability. Disability is no longer seen as gods punishment but it is still viewed with suspicion. [...Earlier Foucauldian analysis]

⁹ patriarchal social structure...power working through this discourse constantly
283, Feminists would argue that there are a multiplicity of patriarchal discourses at work in this scenario. That women should do the caring work. That a woman who cannot do the caring work is not a suitable partner and should be cared for by someone other than her male

[12] Having a disability has a material dimension

*There were five other kids with disabilities at the High School that Kelly attended. While she was there the hours of assistance for teacher aiding was reduced to five hours per student due to school budget cuts. Consequentially Kelly could only have teacher aiding in the class where she needed it most. This was biology because of its high practical component. As the assessment for biology was 50% practical, 50% theory Kelly had to be almost perfect on the theory side because she found it impossible to fulfil the practical requirements. 'The teachers said they gave the same scholastic opportunities but didn't take disability into account because **it wasn't fair on the other kids...** when in the hell was it going to be fair for me?!'¹⁰*

[13] Time:

For people who are not working filling in time can become a major problem.

'I called in to see someone [who has MS] the other day. I thought Jenny was a busy person. I almost didn't call in because I thought I should ring first. She wished she didn't have as much time to fill in her day. I said, I wished there was another 15 hours in the day sometimes... She was nearly in tears... I know what she means though... but I can't recall ever being bored. When I have to get up I think oh Jesus I've got to allocate time for ablutions, have to get up and get going. I think Massey study has been good. It gives you something to do. I almost don't have time to finish things, I wanted to finish

partner. That someone other than a woman herself will be the person to decide when additional caring is needed...

I think that Morag's husbands actions are symptomatic of a sexist society. His opinions and actions are unlikely to have been undertaken by a woman in a similar situation.

¹⁰ 136, Cultural capital theory is a theory of the working class. That they carry with them particular expectations because of their social position. Do you think your first experiences such as the ones described here affect or restrict your options in later life.

sorting some jigsaw puzzles for a friend; making sure all the pieces were there. I felt sorry for Jenny, I thought she was always so busy'. [Stacey]

Being on time can also be a major problem.

'It's the time factor, doctors, taxis... it's hard having a job if you have to rely on taxis. . . If I'm late back to my job from appointments it doesn't make a good impression'. [Margaret]

The extra time it takes to care for yourself, or work around your disability can be a major defining feature in peoples lives.

When taking time out and resting has never been a part of a person's life, it may be a very difficult thing for them to do. [Morag]

Tiredness motivated Morag to try using a wheel chair. She used the chair for some time but gave it up because she found she was losing what mobility she had left. She now uses the chair strategically so as to get the maximum out of her days.

..Margaret is concerned that the number of alternative living situations people with disabilities have to choose from is dwindling. 'I don't agree that there should be institutions but where are they [the people who live there] going to go?.'

Spasms, especially in the early morning, have been another problem Morag had to deal with. They got so violent at one stage that she had a mattress, affectionately termed, 'the crash landing pad', beside the bed. ¹¹

¹¹ 296, 298, 299...Michael Oliver a leading disability theorist has been critiqued for denying the material aspect of disability.

Oliver talks of a social model of disability. That is a model of disability which challenges the personal tragedy model of disability and instead posits that disability is a socially constructed phenomena. Although I agree with Oliver to a certain extent in that he challenges the personal tragedy model I feel that his analysis denies some of the material aspects of disability. For example having a disability can make you tired... it wouldn't matter what the

[13] Uncertainty.

The issue of uncertainty came up often in the life histories.

For people with disabilities which may be progressive, the future is often uncertain.

Some aspects of having MS are not so easily managed. 'The interesting thing about MS is you don't know what will happen next'.

Uncertainty is a major concern when changes in living circumstances are made.

At the age of twenty two, Henrietta left [the institution] with \$65, her clothes, and a box of groceries the staff had collected money to buy for her. Henrietta had no furniture and no bed linen. She didn't even know if food was provided [in the residential setting].

Community care was initially introduced as a cost cutting measure. However, if community care is provided properly it does not cost less than institutional care. This is particularly true at the time of changing over from institutional care to community care as people need support to cope with the changes in lifestyle.

[14] Institutional living may be perceived as a threat or something that would be strenuously resisted if alternative care became a problem.

At one point, Iris threatened that she could no longer supply carers. Visions of institutional care started to plague Henrietta. 'There aren't that many alternative services

world was like you would still feel physically tired. I feel that there are more factors which impact upon the experience of disability. Gender is another important aspect that Oliver touches upon only extremely superficially.

Finkelstein, Vic (1992, July). Revolution. New Internationalist, p. 26-28. Also suggests that changing the material circumstances of disability is the key to the solution. I think it is one key. Again there is no gender analysis.

available. If attendant care doesn't get the contract they're negotiating for at the moment, you can guarantee it [the quality of service] isn't going to be as good'.

...Deinstitutionalisation, normalisation in its pure unadulterated, un-Rodger Douglasified form is what people with disabilities are working towards. But this requires commitment, economic, social, and political. We were starting to get it about five years ago. But there wasn't the time taken to do it properly. Institutions were closed down right, left and centre. [Henrietta]

[15] Oppressed groups should be looking at working together to bring about change¹².

As well as change happening at a government level Henrietta sees the impetus for change coming from the level of individuals and groups within society. According to Henrietta oppressed groups within society should be looking at working together to achieve common goals. 'It's not just a matter of people with disabilities working on their own band wagon. People with disabilities have got to get together with other groups such as women and Maori to work together for similar things. You can't deal with these things in isolation'.¹³

[16] Mobility

From obtaining funding for wheelchairs and paying for prostheses, to obtaining and modifying cars: mobility issues complicated and often frustrating. Non-disabled people take this for granted but because of complex and intrusive application processes, this is another means by which the lives of people with disabilities are scrutinised and controlled.

¹² Weeks radical pluralism.

¹³ 103 I would suggest that we live in a sexist social order. That we need to be aware of the ways in which power works in this society and that it is possible to work collectively (i.e. not just bound by identity) achieve this. I believe that feminist theory and practice used as a way of understanding the lives of women with disabilities and the insights of women with disabilities on what it means to be a women in our society is one of the ways in which we might achieve social change.

Chairs

Now that Margaret has a job she is eligible for a scooter. To get a scooter you have to go through the Disabilities Resource Centre (DRC). Rather than going to the DRC directly, 'which would seem the most logical', it is necessary to obtain a consent form from your GP, visit the Occupational Therapist at the Hospital and then approach the DRC.

Assessment

Going through the assessment rigmarole has paid off. Margaret will get her scooter. The only catch is that she'll have to wait for several months.

Means Testing

Henrietta couldn't get funding for her first wheelchair. Her parents applied for funding for a wheelchair from the Department of Social Welfare, but the application was denied.... CCS bought Henrietta's first wheelchair. Before this she had a buggy major (which is a large pushchair type arrangement). Henrietta got her first motorised wheelchair when she was twelve and a half. What did she think of the motorised wheelchair? 'Great'!

Jane rang Thompson's wheelchairs and told them the name of the chair she had seen on the Television programme. They didn't have it at the time but offered to import it for her. They came over with the brochures and Jane was soon the owner of one of the first electric wheelchairs in New Zealand. 'It was brilliant, it was like a whole new world had opened up itself up to me. The kids loved it, they used to ride on the back on the way to school'. It was extremely expensive but Jane was well able to afford it on her teaching salary. She had a friend in [the town she lived in] who was able to maintain it for her. The chair was driven by a chain belt from the motor, and stones often got stuck in it, so it was handy to have someone on hand to fix it. The only things available in New Zealand

[prior to this] were electric three wheelers, not suitable for Jane's purposes.¹⁴

'About two years after I'd been diagnosed and all that garbage, I got a grant from the lotteries', \$8,000 plus GST. She also saved over \$5000 of her own money. With the money, she bought a Holden Barina. The new car was marvellous. It had five gears, all of which worked, not like on the Triumph Herald where they had only pretended to work. Stacey got her first speeding ticket, \$120 dollars for going 121 kilometres an hour. Fortunately, he hadn't caught her earlier going 140 kilometres an hour.

Car

The largest amount of money [the participant] has been provided with is a loan from DSW. They provided a 'Suspensory Loan' to buy a van three years ago. To qualify for this loan you have to be working, undertaking continuing education or doing a certain number of hours voluntary work in the community. If your circumstances change during the five year period of the Suspensory loan, you have the options of either returning the vehicle, or paying it off in a lump sum. Grants are also available through the lotteries board. Lotteries board grants have to be applied for and are only available to people who make a good case for needing private transport.

The car quest began seven years before the car became a viable reality. The money for the car came partly from Henrietta's own savings and partly from donations from trusts. One trust in particular, the Hutter Trust in Napier, made a substantial donation. The costs of the car have just gone up

¹⁴ 103 I would suggest that we live in a sexist social order. That we need to be aware of the ways in which power works in this society and that it is possible to work collectively (i.e. not just bound by identity) to achieve this. I believe that feminist theory and practice used as a way of understanding the lives of women with disabilities and the insights of women with disabilities on what it means to be a women in our society is one of the ways in which we might achieve social change.

and up and up. The increase in the cost of the car has been affected by the government's refusal to waver import duties on the components for the car. The Government used to be party to the Nairobi Convention Agreement which exempts people with disabilities from having to pay customs and duty. However, the National Party does not adhere to this agreement.

[17] Providing people with disabilities with the opportunity to socialise with children of their own age is considered to be an important issue.

[The participant] was put in a ward with 'people both young and old who had physical and intellectual disabilities.... So I didn't have peer association which everyone talks about as so important. I had nobody to talk to other than when I went to the normal primary school for a while'. However, at the primary school [the participant] missed out on her physical exercises. Eventually she had to return to the [institution] to be closer to the place where she went for exercises. [The participant] missed the classroom competition she had experienced at the primary school. At [the institution] 'the others were all special so they were taught other skills' [The participant] continued her schooling alone. She had enjoyed the normal primary school. 'Disability wasn't a thing to the kids at the primary school'. They were curious but not judgmental.

Accessibility problems combined with the fact that the secondary school teachers didn't consider it to be their job to help somebody to the toilet, meant there weren't many options available to Henrietta. Henrietta was the youngest person at [the institution] for the first couple of years of her stay. There was no room for being a child or a teenager in that environment. You were expected to behave like an adult. It was a long way from her parents and family as well. Henrietta only went home to visit in the school holidays. As [the institution] was so far from home family visits to Henrietta were also relatively few and far between. The isolated hill top location of [the institution] meant Television and [the

institution] became the limits of Henrietta's world. Communication with the family about other things became very difficult due to the lack of shared interests, and visits became increasingly strained.

[18] Having a disability is expensive.¹⁵

'The other thing about disability, probably physical disability especially, is that you have a lot of extra costs added... costs incurred because of your disability. Chairs wear clothes badly. I need to buy cloths which are light and warm otherwise I can't move my arms. [It's] an added expense to the cost of living'. Added to this is the cost of paying someone to do things, such as mow the lawn. 'At fourteen thousand you lose your disability allowance... we should get a disability allowance as a right'. If Jane needs extra home help, she has to find the extra money herself.

'...having special clothing needs makes it virtually impossible to take advantage of sales. If you need to have special shoes made, it means they usually cost more than an average pair of shoes, it also means you never have the opportunity of buying good shoes on sale'. Jane terms the inability to take advantage of sales one of the luxuries you don't get.

There are other less than obvious costs associated with disability with which Jane has to contend. Compensating for a weak grip by holding things in her teeth has brought about dental problems; broken teeth being the most extreme example. Jane's high dentist bills can be directly attributed to disability. The dentist has warned her that he can't build her teeth up again. 'Income support take an average income (as their baseline) and don't take the extra costs of disability into account at all'.

Disability allowance is another form of help available to Stacey. This is 'supposed to cover so many things. Lawns, extra heating, different types of foods, special clothing,

¹⁵ Bourdeau.... defining..can be liked to a class analysis... cultural capital theories

anything used as an extra...petrol for doctors and many other things. There's no bloody way it would pay for half of it. Thirty seven dollars a week an amazing amount!

Disability allowance also doesn't cover things like all the extra toilet paper you use when you go to the toilet or the fact that things can be more difficult. Tampons are often dropped down the toilet for example. 'I use up twice as much stuff as I used to'.¹⁶

Having a Disability and Living on Your Own

Margaret was well supported by friends and family when she first moved into her own house. Margaret's first forty-eight hours in her own place were very different from her previous life. She had no telephone, no television and nobody else to talk to. The strangeness and loneliness of the situation upset Margaret, and she shed a lot tears in those first few days. 'I used to sit in the corner listen to my tape deck and bawl my eyes out... all of a sudden I was out in the community and it was good... but I didn't know anybody from Adam and [after the telephone was installed] I used to ring up my friends and bawl'.

Although the move from living in an institutional situation is traumatic it is still perceived to be a far superior living arrangement. However, there is a need for this to be better supported.

¹⁶ 454, 455...Extra cost of having a disability is well documented in the disability literature... in current political climate things are unlikely to change.

ERRATA

PAGE	LINE	CORRECTION
51	11	<i>Delete</i> commas on either side of McNay's date (1992).
75	<i>5 from bottom</i>	Yeatman (not Yeatman's) should be in brackets as well as date
81	13	<i>Delete</i> space in the word main stream
114	5	it's <i>should read</i> its.
159	7	<i>Insert</i> 's in the word Gods
180	1	<i>Insert</i> 's to the word persons
215	<i>12 from bottom</i>	<i>replace</i> participants <i>with</i> participants'