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**MULTIPLE CHOICE? THE EXPERIENCES OF
WOMEN WITH MULTIPLE SCLEROSIS:
OPPRESSION, OPTIONS, OPPORTUNITIES.**

A thesis presented in partial fulfilment of the requirements for the degree of
Master of Social Work
at Massey University, Palmerston North, New Zealand.

Susan (Sioux) Elisabeth Natasha Green

2001

DEDICATION

This thesis is dedicated to the memory of

Maureen Elenor Walsh

27 October 1943 - 08 October 2000

and

Andrew Leslie Cantwell

22 November 1955 - 19 December 2000

and

Mike John Deane

31 May 1955 - 05 January 2001

in recognition of their friendship and support
for the completion of this work.

ABSTRACT

This thesis examines the ways in which women with Multiple Sclerosis (MS) experience disability as their disease progresses over time. Underpinning my analysis of the process of becoming disabled is a critique of the ways in which a combination of patriarchal discourse and the medicalisation of disability result in the social construction of disability. This study contends that such a construction can exclude and oppress women with MS, reducing their choices in life.

Additionally, this research examined whether or not the alternative discourses of feminism and the social model of disability offered women with MS options for politicising their experiences and opportunities for empowerment and emancipation.

Seven women participated in in-depth interviews. Additional information was obtained from documentation provided by six of the participants. Finally, one male was interviewed and provided documentation about his recently deceased wife's experiences of MS which was presented as a case study separate to the main body of the data.

Themes which emerged from the data suggested that the greater the number of oppressive variables present in a participant's life, the higher her risk of social oppression and exclusion appeared to be. Counterbalancing this, the greater her access to appropriate assistance, alternative discourses and strategies of resistance, the more she seemed enabled to resist disability as social oppression.

Emerging themes around the political issues of oppressive and inadequate welfare assistance, fragmented and uncoordinated health and care systems and poorly actioned employment and human rights policy are discussed; as is the civil rights issue of the underfunding, non-subsidisation and capped budgets for medical treatment of people with Multiple Sclerosis which promotes exclusion and dependency.

The aim of this thesis is to highlight these themes, to offer alternative discourses of the social model of disability and feminist theory as options for empowerment, and to politicise the experiences of this group of women. In so doing, the aim of this thesis is also to inform professionals and policy makers of the very real need to promote a politics of difference and inclusion, rather than oppression and exclusion for women with Multiple Sclerosis.

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CONTENTS

	Page
PART ONE: THE RESEARCH	
Chapter One: Introduction	1
Chapter Two: In From the Margins: Theories of Disability	13
Chapter Three: Research Methodology and Design	39
PART TWO: OPPRESSION? DATA RESULTS & DISCUSSION	
Chapter Four: What is Multiple Sclerosis?	64
Chapter Five: Foucault, Medicalisation and Multiple Sclerosis	82
Chapter Six: Oppression? The Social Model of Disability and Multiple Sclerosis	107
Chapter Seven: Oppression? Feminism, Disability and Multiple Sclerosis	138
Chapter Eight: In From the Margins: Lived Realities of Disability	168
Chapter Nine: Public Policy, Private Pain	179
PART THREE: OPTIONS? OPPORTUNITIES?	
Chapter Ten: Multiple Choice? Conclusions and Recommendations	194
PART FOUR: REFERENCE MATERIAL	
Appendix One: Massey University Ethics Protocol	211
Appendix Two: Interview Format for Participants	228
Appendix Three: Copy of Personal Narrative sent to Participants	231
Appendix Four: Glossary of Medical Terms	248
References	253

LIST OF ILLUSTRATIONS

	Page
Figure 4.1: Multiple Sclerosis Symptoms (Past and Permanent) Experienced by Participants.	77
Figure 5.1: Participant References to Negative Experiences of Power, Subject/Object Position and Internalised Discourse.	92
Figure 5.2: Participant References to Positive Experiences of or Resistance to Power, Subject/Object Position and Internalised Discourse.	92
Figure 6.1: Participant References to the Experience of Powerlessness or Worthlessness and the Experience of Disabling Constraints as Social Oppression.	114
Figure 6.2: Participant References to the Experience of Empowerment or Being Valued and the Experience of Enabling Assistance as Social Emancipation.	115
Figure 6.3: Participant References to the Experience of Powerlessness or Worthlessness at Different Societal Levels.	115
Figure 6.4: Participant References to the Experience of Empowerment or Being Valued at Different Societal Levels.	116
Figure 6.5: Social Oppression Theory: Participant use of Strategies, Resistance and a Politics of Change.	116
Figure 7.1: Participant References to the Experience of Invisibility / Not Being Heard and to the Experience of Hiding Impairment.	151
Figure 7.2: Participant References to Strategies or Resistance to Experiences of Invisibility and Hiding Impairment.	151
Figure 7.3: Participant References to Positive and Negative Experiences Relating to the Concepts of Time, Work and Productivity.	152
Figure 7.4: Participant References, Positive and Negative, Relating to the Dependence-Independence Dichotomy.	152

	Page
Figure 8.1: Total Number of References to Negative Experiences: Foucault and Medicalisation, The Social Oppression Model and Feminist Theory.	173
Figure 8.2: Total Number of References to Positive Experiences: Foucault and Medicalisation, The Social Oppression Model and Feminist Theory.	173
Figure 8.3: Total Number of Responses to Negative and Positive Experiences and References to the Impact of Multiple Sclerosis.	174

PART ONE:

THE RESEARCH

CHAPTER ONE

INTRODUCTION

Multiple Sclerosis (MS) is a progressive neurological disease affecting the central nervous system. Within the brain and spinal cord, nerve fibres are surrounded by a fatty substance called myelin which is gradually destroyed as a consequence of the disease process. The destruction of myelin occurs in many scattered areas of the central nervous system, and the damaged area becomes filled with hardened material, or scars called plaques or sclerosis. It is from this process that the disease is named - Multiple (many) Sclerosis (scars).

As a result of the process of demyelination, varying degrees of physical symptoms and impairment occur for people diagnosed with the disease. Multiple Sclerosis follows a varied and unpredictable course depending on where damage is located within the central nervous system and how frequently myelin is attacked over time. It is therefore highly individualised in its course, severity and in the level of impairment experienced by those diagnosed with MS. Multiple Sclerosis has no single identifiable cause, is difficult to diagnose and has no cure. It affects women more frequently than men, and is found more often in countries far south or north of the equator. Aotearoa New Zealand is therefore identified as a high risk zone for this disease.

The Purpose of this Research

This research aims to examine how women with Multiple Sclerosis experience disability as their disease progresses over time. Underpinning my analysis of the process of becoming impaired (or disabled) is a critique of the ways in which a combination of patriarchal discourse and the medicalisation of disability result in the social construction of disability. I will debate that this construction can exclude and oppress women with MS, reducing their options

in life perhaps more profoundly than their impairment does as the disease progresses. While it could be debated that the medicalisation of disability oppresses men with Multiple Sclerosis in a similar way, I will propose that the combination of this model and patriarchal discourse can cause women with MS to experience this oppression in a qualitatively different manner.

I will suggest that feminist discourse and the social model of disability offer points of resistance to the medicalisation of disability, providing opportunities for politicising the personal experience of impairment. Furthermore, in applying these alternative paradigms to the experience of living with Multiple Sclerosis, I will propose that they offer options and opportunities for empowerment and emancipation.

Concept Definitions

For the purposes of this study, the following definitions, drawn from the *Fundamental Principles* document developed by The Union of the Physically Impaired Against Segregation (1976) are proposed:

Impairment: 'lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.'

Disability: 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Disability is therefore a particular form of social oppression'.

Therefore, references made to a participant's impairment will refer to the physical effect(s) of their disease, while reference to their disability relates to

the social construction of disability. Exceptions to the above definition will be restricted to direct quotes from authors and the research participants themselves. For definitions of the concepts of medicalisation and patriarchy, refer to the fuller discussions within Chapters Two and Five to Seven.

A Personal Journey

My selection of this topic developed from a long standing interest in the fields of disability and feminist discourse. This interest became more personal when I was diagnosed with Multiple Sclerosis in 1997. My own experiences of others' responses to the process of my diagnosis and to the rapid progress of my disease raised numerous personal questions as to how society reacted to illness and impairment. These experiences have been attached as Appendix Three of this thesis.

As I talked with other women diagnosed with the disease, it became apparent that many of them had become excluded at several levels of society to varying degrees. As impairment had progressed or for some, at the point of diagnosis, a process began which was driven not necessarily by the disease, but by society's response to it. This process had resulted in their gradual exclusion from involvement in work, leisure activities and their community in general. The degree to which this occurred seemed to depend on a complex interaction of factors, including:

- the ways in which the disease manifested itself in each of them and their personal experience of the disease process
- the level of support they received from friends, family and wider society to remain involved in their community

- whether or not they had internalised the discourses of patriarchy and the medicalisation of disability in that they accepted that their current roles and situation were due to the impact on them of their disease and / or were a 'natural' or 'expected' position (defined by patriarchal or male dominated society) for them as women
- whether or not they had access to an alternative discourse which challenged their position as being, to a greater or lesser degree, created by the society in which they lived; and were supported in utilising it to resist such medicalisation.

While my studies of feminist thought enabled me to debate that some of these experiences might stem from patriarchal discourse (for example, Spender, 1983; Bryson, 1992; Du Plessis, 1992), the majority of writers had not applied this to the experiences of impaired women, so failed to explain adequately the societal responses experienced by myself and the women I spoke to. Further studies introduced me to the social model of disability developed particularly by Vic Finkelstein (1975, 1980) and Michael Oliver (1990, 1996) which offered many responses to those questions left unanswered by feminist discourse.

From these experiences, my interest developed further in terms of whether or not other women with Multiple Sclerosis had experienced a similar process of what both feminist thought and the social model of disability defined as oppression. The intent of this research therefore is to gain an understanding of the lived experiences of a group of women with MS, through their personal narratives and the meanings they ascribe to their own process of impairment and the personal impact of society's response to it. It is also to gain an

appreciation of what occurred or might occur if women resisted these societal responses.

In my conversations with local women with Multiple Sclerosis, many revealed how their experiences had become silenced - how over time, what they had to say about their lives and experiences was not heard by medical professionals, their workplaces, welfare agencies and the community at large. This research then also seeks to provide a voice for women with MS, and anticipates that their narratives have much to contribute to the alternative discourses offered by the social model of disability and by feminism.

Oppression? Options? Opportunities? The Research Questions

The purpose of this research is to study the lived experiences of women diagnosed with Multiple Sclerosis. What I hoped to discover at the outset was whether or not their experiences of the disease process and the impairment accompanying it supported or refuted the theory that disability is a form of social oppression arising from discourses of power and the medicalisation of the condition by society. Furthermore I intended to examine the impact of patriarchal discourse upon these experiences to ascertain to what degree feminist thought applied to the lives of women who daily deal with the disease. The following two research questions were formulated as a result of these aims:

Does a combination of patriarchal discourse and the medicalisation of disability oppress and exclude women with Multiple Sclerosis from society, thereby reducing their options in life more than their progressive impairment?

and stemming from this:

Do the alternative discourses of feminism and the social model of disability offer women with Multiple Sclerosis options for politicising their experiences and opportunities for empowerment and emancipation as a consequence?

Given that Multiple Sclerosis is a complex and highly individualised disease that impacts upon people to varying degrees and in ways which can be invisible to the general population, I did not undertake this research in order to evidence a predetermined political agenda - I anticipated that the disease, by its very nature, should test both the medical and social model of disability - the fact that it is a disease process rather than a stable impairment suggested a tension could exist between the two. It was because of this possibility that the primary focus of this research was on the lived experiences of those interviewed and, more importantly, on the meanings they ascribed to those experiences.

The Personal is Political

My own experiences were politicised from an early stage, which meant initially I planned not to include them in this study (Refer to Appendix Three for these experiences). I felt that given that I had adopted a particular viewpoint for my own life, to include my own experiences could skew the outcome of this study, reducing any objectivity implied by the research questions - after all, the women I planned to interview had not, to my knowledge, had access to the same theoretical base as I, and could hold very different views as to the meanings they ascribed to the disease and to impairment.

What I did not anticipate however, was that I would encounter a negative response to this research from the one area I believed had good reason to

support this study. That is, the Research and Advisory Committee of the Multiple Sclerosis Society of New Zealand decided not to support this enquiry, a decision which altered the research design significantly, reducing my options as a researcher, as well as opportunities for women with Multiple Sclerosis to choose to participate. While their response is detailed in Chapter Three of this thesis, at this point it is enough to suggest that, by their very nature, the research questions caused a sense of controversy and disquiet within this committee.

Their response exposed to me the very political nature of disability as social oppression as well as the politics of research. As a result of that response, and in order to respond to it, my own experiences have been included as **one** of the narratives of women whose lives with Multiple Sclerosis are presented in the following chapters. That is, in order to be true to the research paradigms I proposed to utilise, I became a formal participant of this research, as well as an observer.

THE RESEARCH

Research Paradigms

In order to undertake this research, I made the decision from the beginning to make use of qualitative and emancipatory research paradigms recommended by both feminist (for example Stanley & Wise, 1990; Smith & Noble - Spruell, 1986; Oakley, 1981) and disabled (including Oliver, 1990, 1992; Morris, 1992 and Finkelstein, 1980) researchers. While I have elaborated further on the paradigms in Chapter Three, the purpose of emancipatory research is to bring in from the margins the lived realities of the participants and of impairment. It is also about reciprocity between researcher and researched. And finally, it is about social and political action to bring about change.

By selecting such an approach, my responsibilities to the participants involved in this study must therefore take precedence. What this has meant for me is that while this is an academic enterprise, this thesis has as its central core, the narratives of the participants; in effect, they have become co-authors of this piece of work. What it also means is that I have endeavoured to ensure that the participants who have contributed their time, energy and knowledge have not wasted that - that their experiences, recorded throughout this study, are made available to others to inform, to educate, and to provide options and opportunities for change.

An Emancipatory research paradigm, with its focus on and commitment to a more equal and empowering relationship between the researcher and researched lent itself well to the development of collaborative working relationships between myself and the participants of this study. At the same time, it demanded much of me in terms of transparency, honesty and integrity with its focus on reciprocity and political change.

It was due to these demands, that I became aware of a growing sense of unease while planning the presentation of this thesis. The unease lay, on reflection, in the ways in which I would present the data obtained from the research participants. I had followed the emancipatory principles of beginning with the narratives of the women I had interviewed - the 'telling of their stories' (Rheinhartz, 1992; Munford, 1992, 1995; Hillyer, 1993; Haber, 1994) so important to being able to develop a critical analysis of the experience of impairment and disability and to being able to present it from the 'bottom up' (Williams, 1990, Munford, 1995; Perkins, 1998).

In the process of my data analysis, each woman's story, while being scrutinised in terms of how the various theoretical constructs applied to it, essentially remained intact. That is, my intent was not to make the women's experiences fit the theories - a disempowering and alienating approach reminiscent of positivist research paradigms (Oliver, 1992) - but to ascertain whether the **theories** had anything to offer in terms of options and opportunities for the participants. In this way, their narratives remained central to the research.

However, I faced a considerable dilemma in the presentation of their data. Within an academic enterprise such as this, the data obtained is generally presented as a stand alone results section, and is followed by discussion, and / or recommendations and conclusions. However, as Lovett describes:

Instead of stories, we focus on incident reports. Instead of a person's history and personality, we give data (1996:52).

The attempt to write using the conventional format resulted in what I perceived as a disturbing shift in what was occurring with the data obtained - that after accusing former writers of this very issue in Chapter Three, the women's stories were becoming **lost in the academic shuffle**. Their narratives, so generously given, were being reduced to a single chapter that made up less than a third of this thesis. They became, in effect, data providers, and ceased to be the co-authors of this research.

Frustrated by my attempts to somehow broaden their involvement within this work, I wrote what has become Chapter Four. That is, I laid out the clinical framework of the disease Multiple Sclerosis and then immediately followed it with the experiences of the participants. Their experiences of the physical aspects of the disease became **immediately visible** using this format, and

were not lost. Even though their experiences were presented in summarised form to preserve their privacy, each participant remained present, acknowledged and a key contributor to the research.

In applying theoretical constructs to the data obtained, again the 'norm' within a piece of academic writing is to discuss the theory at length within a literature review, then following the presentation of the data results, to interpret what those results mean in relation to the theory. Again, in attempting to do so, the participants' information became fragmented and **lost**.

In recognition of this issue, and in an attempt to prevent this from occurring, I have adopted a different approach. That is, while having discussed briefly each of the theoretical underpinnings of this study within the literature review, I have postponed an in-depth presentation of the theories involved until the later data and results section of this thesis in order to lay the theories alongside the lived experiences of the research participants. Instead of fragmenting the participants' data in a disempowering manner, I have initially, fragmented the theory.

What this means is that Chapters Five to Seven will be written with a similar structure to Chapter Four: the theoretical argument will firstly be presented, followed immediately by the lived experiences of the participants - experiences which both confirm and refute the theoretical constructs, experiences that immediately contribute to the theory, without being lost in the academic shuffle.

The Structure of this Thesis

The purpose of this chapter has been to introduce the reader to the general background and research questions which have formed the foundations for the

remainder of this piece of work. It also briefly introduces the disease, Multiple Sclerosis, which is focused on in more depth in Chapter Four. This thesis has been divided into four parts, which reflect the process undertaken with this research. Part One consists of Chapters One to Three, with Chapter Two comprising a review and critique of the current theories and debates occurring within the field of Disability Studies, and which are being questioned by this study. Chapter Three outlines in detail the research methodology and design of this research, both as it was originally planned, and in terms of the changes that occurred as a result of the disquiet the research questions caused.

Part Two (**Oppression?**) presents the results of the data obtained and discusses the results with regard to the theories being critiqued. This section is divided into five chapters, with Chapter Four presenting a more detailed discussion of the medical aspects of Multiple Sclerosis. Chapter Four also introduces the reader to the participants of this study and their experiences of the medical aspects of MS are discussed parallel to the clinical information presented.

This process is followed throughout the next three chapters which form the bulk of the discussion around the results obtained from the data collected. Chapters Five to Seven debate more fully how the data applies to the theories in question, beginning with an examination of the medicalisation of disability (Zola, 1977) and the application of Foucault's (1973, 1977) analysis of power as it relates to the experiences of the participants. This is followed by a discussion of the social model of disability with regards to the data obtained from this research (Chapter Six) and a feminist analysis of the data in Chapter Seven. A summary of the data obtained from the study is presented in Chapter Eight.

This section concludes with Chapter Nine presenting a case study of Ruth, in which the experiences of one woman and her husband are discussed as an example of how discourse, oppression and social policy in this country combined to systematically reduce their options during the last five years of Ruth's life. This case study draws upon the discussions of the previous chapters to consolidate the data presented, and concludes that the combination of patriarchal discourse and medicalisation can oppress women with MS in ways which can be more profound than their progressive impairment.

Part Three (**Options? Opportunities?**) The final chapter presents the conclusions developed as a consequence of this research, and makes a series of recommendations with regard to those conclusions. Additionally, this chapter examines and discusses the processes of this research, including the strengths and weaknesses of the study, and suggests possible future directions for studies into living with this disease. Finally, Part Four concludes this thesis with a reference section and appendices.

CHAPTER TWO: IN FROM THE MARGINS: THEORIES OF DISABILITY

INTRODUCTION

Chapter One of this thesis introduced a different definition of the concept of 'disability'. To redefine disability in such a way can profoundly alter the ways in which people perceive, talk about and behave towards impaired people. It can also profoundly alter the views impaired people hold of themselves and of the communities in which they live; and in so doing, offers them 'windows of opportunity' (Ballard, 1994) to begin to agitate for change within society. Such a redefinition is therefore a political act, and can be very unsettling for all concerned.

This chapter presents an overview and critique of some of the rising tide of literature that has led to the redefinition of disability as social oppression and the demand for political change at all levels of society. The purpose of presenting such an overview is to introduce the reader to the theoretical underpinnings of this research and to examine some of the debates that have emerged as a consequence.

The structure of this chapter reflects the framework which is used to present the data in the results and discussion section of this thesis. In order to address the research questions of this study, the review of literature firstly discusses the concepts of discourse, knowledge and power, particularly from a Foucauldian perspective, and then presents an historical overview of the medicalisation of society and of disability as one such discourse.

Following this, the social model of disability is discussed and critiqued; and similarly , a feminist analysis of disability and critique of patriarchy is presented. These three sections form the foundation stones for the more

detailed discussion of Chapters Five to Seven of this thesis. Consequently, in the interests of avoiding unnecessary replication of information, this section is relatively brief. A review of literature relating to social policy and practice issues as they relate to disability is also presented. These issues are discussed in greater depth throughout the results and concluding sections of this thesis.

Finally, this chapter presents the issue of research as social oppression, and outlines my reasons for presenting the results of this study in a manner which deviates somewhat from the academic 'norm'; and which leads into the following chapter on research methodology and design.

DISCOURSE, KNOWLEDGE AND POWER.

The past three decades have witnessed an increase in the numbers of disabled people challenging the commonly accepted ideologies and theories around disability. Based within their lived experiences of disability, their speaking, writing, arts and public actions are tackling head-on the status-quo which has 'subjugated their knowledge' (Foucault, 1980).

Common themes which emerge throughout these critiques include the rejection of the 'medical model' of disability (Finkelstein, 1980; Oliver, 1990, 1992, 1996; Morris, 1991, 1992; Rioux, 1994; Munford, 1995, 1998; Munford & Sullivan, 1997), and the development and articulation of sociological and socio-political models of disability (Oliver, 1990, 1996; Morris, 1991, 1992; Ballard, 1994).

Invariably underpinning these themes are the concepts of discourse, knowledge and power. In order to better understand the theories and models of disability, it is necessary to gain an appreciation of the ways in which these concepts combine and are structured by and within a given society.

Understanding Discourse, Ideology and Knowledge.

Discourse.

Discourses, most simply defined, are the 'ways in which members of a society express in language the things that happen to them. Discourses may express ideas, events, actions or relationships...' (Lovenduski & Randall, 1993:58). Discourse is never static - how one expresses their reality or their understanding of events is influenced by their cultural and belief systems, their knowledge base and socialisation and their particular place in time to name a few. As any of these factors may change, so too, the discourse of an individual - or that of an entire society may change over time.

Lovenduski & Randall go on to suggest that discourses can be a form of power (1993:58). With regard to how impaired people are perceived and treated in our society, this concept has been debated at length. Various writers suggest that societal discourse acts in complex ways to develop and maintain certain notions of what is 'truth' about impaired people (for example, Munford, 1992, 1994a, 1994c 1995) which defines and socially constructs them as different in a negative way. Such discourses attribute an 'inferior' status to them (Munford, 1994c:6), can marginalise and silence them within a discourse of what is for the 'common good' (Weis & Fine, 1993:1) and are used to control the ways they are treated within society (Munford, 1995:30) given the position attributed to them.

Political discourses determine what services are provided to impaired people, and tend to reflect the overall societal discourse at any given time. If societal discourse therefore expresses impairment as a negative construct and as undesirable, the social and economic policy decisions will reflect those views (Barton, 1992). Munford argues that the processes of social policy are never neutral (1994:9), but are a 'reflection of competing interests'.

Ideology

Abberley argues that all discourse is intrinsically ideological, and draws on Thompson's (1984) assertion that ideology serves to 'sustain social relations which are asymmetrical with regard to the organisation of power' (1984:6). Thompson identifies three key ways in which ideology does this. Firstly, it *legitimizes* power - it gives authority to particular individuals, classes or social groups and legitimizes their collective views. Secondly, it maintains the *interests* of powerful groups or individuals by offering a particular social reality acceptable to their views; and finally, it *universalises* the social reality mentioned above, (through discourses) in order to make it appear to be an 'inevitable and enduring aspect of human experience' (Abberley, 1995:222).

Ideology therefore enables the norms or value base of a dominant group to be perceived as superior (Munford, 1995) and serves their interests (Wearing, 1986). In so doing, the discourse of the dominant group becomes legitimate, often at the expense of silencing other minority or vulnerable, but according to Haber, 'no less valid' (1994:116) voices. From such a perspective, ideology and discourse thus also define what constitutes 'knowledge'.

Knowledge

Stanley & Wise assert that 'all knowledge results from the conditions of its production, is contextually located and bears the marks of its origins in the minds and practices of those who give it voice' (1990:39). Knowledge is therefore neither neutral nor impartial; it is underpinned by the ideology of (usually) the dominant discourses of society. It is 'produced within power relations and functions to legitimate particular kinds of truth' (Munford, 1992:11).

An analysis of discourse, ideology and knowledge can enable social researchers to make a critical assessment of how it is that certain discourses define the ways in which particular individuals or groups in our society are treated by others and how they construct our reality. Inherent in such a critique is an examination of how power relations contribute to and maintain the dominance of certain discourses at the expense of others.

Understanding Power

In developing an understanding of how discourse, ideology and knowledge legitimate the dominant position of some groups in society rather than others, it is possible to conceptualise power within the lives of disabled people. Wearing's feminist analysis of power perceives the concept as a 'relationship between dominant and subordinate groups which is underpinned by ideology' (1986:34), while Van den Berg & Cooper (1986) debate that the control of power promotes dependency by not allowing individuals to control their own lives, leading to powerlessness.

Disabled writers such as Michael Oliver, Vic Finkelstein and Jenny Morris debate the issue of power in terms of disability and writers such as Munford (1992, 1995), Ballard (1994), Williams (1990), Barnes & Oliver (1995), Findley (1995), Sullivan & Munford (1998), examine the issues of disability, power and the impact of social policy on impaired people. This study, while drawing upon these analyses of power, focuses on a Foucauldian analysis of power as it relates to the experiences of women with Multiple Sclerosis.

Michel Foucault: Power, discourse and knowledge

Michel Foucault's main interests lay in the ways in which individuals are constructed as social subjects, 'knowable through disciplines and discourses'

(Allan, 1996:220). His aim was to 'create a history of the different modes by which, in our culture human beings are made subjects' (Foucault, 1982:208).

Foucault's earlier works (1967, 1972, 1973) used what he termed an 'archaeology' to develop a 'descriptive account' of discourses, of statements that in history, represented the truth (Davidson, 1986). Foucault's focus within this archaeology was on the disciplinary mechanisms within prisons, lunatic asylums and hospitals, from which he developed his analysis of power. While this analysis is discussed in greater depth in Chapter Five, Foucault's analysis of power draws on a combination of disciplinary mechanisms or 'tools' (Foucault, 1977) by which power maintains its 'omnipotence' (Ibid:170). These tools include *Hierarchical Observation*, *Normalising Judgement* and the *Examination* which combine to 'maintain an individual in his [sic] subjection' (Ibid:187).

A central theme within Foucault's archaeology is the way in which the clinical 'gaze' (Foucault, 1973) constructs individuals as both subjects and objects of knowledge and power. In his later works, which he termed as 'genealogy' (1976, 1977), he focused more on power and knowledge relationships within institutions, and later debated that 'objective, disinterested knowledge...' (or knowledge seekers) '...was not possible (Foucault, 1984) - that discourses were created within a particular historical, spatial and institutional context and that discourses produced, but also policed knowledge (Featherstone & Fawcett, 1994).

Foucault's analyses of power, discourse and knowledge have been applied to the area of disability studies by a number of writers. Sullivan (1996) provides a compelling description of the ways in which paraplegic bodies are constituted as subject, as does Allan (1996) when applying a Foucauldian analysis of the

use of normalising judgements, examination and observation of children with special educational needs. Munford (1992, 1994a, 1994b) looks at the ways in which not only disabled people, but also their caregivers are drawn into and under the 'gaze' of professionals and society, and provides a feminist analysis of how women's bodies become objectified as disabled women.

Other feminist writers also examine the ways in which the technologies of power, particularly through patriarchal discourse, impact on disabled women in such a way that they become marginalised, invisible (Lonsdale, 1990), feel obliged to 'hide' their impairments (Stone, 1993); and how women lose control over what happens to their bodies as others define what they are able to do or not (Hillyer, 1993).

Foucault's work is not without its critics however and he has been criticised on a number of fronts. Firstly, in failing to suggest ways in which to create change, he has been labelled a 'pessimist' (Habermas, 1986). While Foucault does advocate resistance and action to effect change (1979), he is criticised for not prescribing how to go about undertaking such action (Shumway, 1989). Fairclough suggests that even though Foucault discusses resistance, he 'gives the impression that resistance is generally contained by power and poses no threat' (1992:57). However, Featherstone & Fawcett assert that Foucault was more concerned with addressing the 'how' rather than the 'why' of power relations (1994:7), leaving ideas for social change or action for others to pursue.

The work of Foucault has significance to this study particularly in terms of his archaeological analysis of discipline, the clinic and power relations. The relevance of this to the experiences of illness and disability, in this case due to the disease Multiple Sclerosis, is addressed in greater depth in Chapter Five

where Foucault's work is applied to the experiences of the research participants.

THE MEDICALISATION OF SOCIETY

When one considers Foucault's (1973) analysis of power within hospitals and asylums, and the ways in which discourse operates to legitimate ways of thinking and behaving, the medical model becomes easier to understand and critique in terms of its impact on disability and impaired people. Additionally, by developing an historical picture of the development of medicine and medical thinking, the medical model can be placed within the historical context which allowed it to flourish and 'medicalise' (Zola, 1977) many facets of daily life, including the daily lives of impaired people.

In his article *Healthism and Disabling Medicalisation*, Irving Zola discusses how medicine has gained power through an historical and gradual development over centuries of a 'scientific' knowledge base which has been used to medicalise many facets of daily living. Beginning with an analysis of the historical development of this situation, Zola examines the weakening of early religious influence which led to the development of common law, the impact of the industrial revolution followed by the emergence of formal law to both explain and control a variety of human relationships.

Zola argues that the post world war trials of Nuremberg and Jerusalem created a 'crisis of jurisprudence' (1977:46) in which the law could not, under questioning, be sustained as a purveyor of 'truth'. This crisis created a vacuum which a developing medical science filled, and which constructed a new 'truth' - a new discourse and authority. Gaining an early acceptance in the United States of America, medical science spread as an authority to encompass much

of the world. This movement, coupled with a respect for scientific knowledge and humanistic ideals of helping others created a powerful entity over time.

In arguing that the medical profession has been able to *medicalise* society, Zola identifies four concrete ways medicine has ensured this can occur. Firstly, he claims, by expanding what is deemed relevant to the good practice of medicine (including extending into the areas of rehabilitation, psychiatry and psychosomatic medicine), while secondly retaining absolute control over certain technical procedures; particularly the right to perform surgery and prescribe drugs.

The third factor is that medicine has retained near absolute access to certain 'taboo' areas - medicine's 'almost exclusive license to examine and treat' (1977:56); and he argues that any part of human life which can be related to the functions of the body can be labelled 'illness', and becomes a medical problem. Examples he gives of this include redefining natural processes such as childbirth and ageing as medical problems, and the prescription of drugs to regulate natural processes such as sleep and emotions.

Finally, Zola suggests that medicine has expanded in terms of what it deems relevant to the good practice of life. He describes this as the role of medical science in 'creating the good life or fending off the bad one' (1977:59), focusing particularly on the use of genetics as a deselection process for removing the 'bad'.

Zola's fears at the time of writing were that such a deselection process would result in medical science heightening some characteristics and eliminating others for the 'good' of society. Today those fears have been more than realised (Beers, 1991; Morris, 1991; Fitzgerald, 1996).

The Medicalisation of Disability

Discourse, Ideology and Power

When applied to disability, the medicalisation of society described by Zola locates disability as a medical concern, defining disability in terms of what happens to individuals at the level of the body - the medically defined difference or 'pathology' those bodies exhibit. Those definitions therefore are generally couched in negative terms. Wicks asserts that:

who and how people with disabilities are, has been commonly defined by people without disabilities... the definitions have historical usage, are pervasive and are based on negative stereotypes of passivity, dependence and helplessness. She goes on to add, There are also ostensibly positive stereotypes like 'supercrip' [or] 'overcoming adversity'... They are just as pernicious, because they imply that all that's needed is for disabled people to struggle harder (1996:2).

Such definitions present and define disability as 'some chance event which occurs at random to unfortunate individuals' (Oliver, 1996:32), what Oliver calls 'personal tragedy theory' which is the ideological underpinning of what is termed the 'medical model' of disability. Such a model, according to Ballard pathologises disabled people within fixed positions. He states:

What tends to happen in this 'sickness' or 'medical model' of disability is that people are labelled as damaged or inadequate and are subsequently viewed almost exclusively in terms of their 'problems' or 'deficits'... they are assigned a 'perpetual client' or 'patient role' (Ballard, 1994:8).

Barton (1993:237) argues that this approach legitimates 'an individualised, homogenised and static view of disability' which assumes some ideological 'norm' to which impaired people are constantly being compared. Barnes (1992) asserts that this view medicalises disability, and in so doing, assumptions are made that it is individual impairment which restricts life chances - little consideration is given to the environments which can disable. Disability is

therefore seen as a 'condition' which requires 'treatment' (Georgeson, 1994) or a 'cure' to return an impaired person to (or as close as possible to) the 'norm'.

If it becomes obvious that this is unlikely to occur, the focus of the medical profession shifts to encouraging an individual to adjust psychologically to their 'loss'. In some cases, more frequently in the past than today - although it still occurs, the incurably disabled or those whose conditions are offensive to society's normative standards are 'removed' - to institutional care as 'deviants' (Thompson & Anderson, 1996), discouraged from reproducing (Brown, 1994; Thompson & Anderson, 1996) and 'cared' for by the very profession which has 'diagnosed' them as requiring such exclusion.

Assessment and treatment processes are consequently couched in terms of deficit theory (Hahn, 1986; Munford, 1995; Allan, 1996), in which individuals are assessed on the ways in which they fail to adapt to the normative measures of the society in which they live. And, given that medical opinion generally determines eligibility for the provision of services, the power of the medical model predominates (Lonsdale, 1990). These measures serve to exclude or discriminate people from many areas of mainstream life. Morris considers this as a form of segregation (1991:117) underpinned by 'Disablism' - which she defines as the 'ideological part of our oppression' (Ibid:117).

Zola argues that the medicalisation of society has far reaching political consequences. He suggests that the increasing use of medical labels for social problems ensnares them as 'illnesses' within the individual, which 'blinds us to larger and more discomfoting truths' (1977:62). Such labels construct social problems such as disability as something to be treated or eliminated which, if supported by mainstream society, means an individual, once labelled, must be treated, regardless of the wish of the individual (1977:63).

However, some writers debate this social constructionist view, arguing that 'labelling' at times is a useful or necessary means by which to either access assistance for those with specific needs (Soder, 1989; Allan, 1996), or, for example in the diagnosis of Post Traumatic Stress Disorder, to develop an understanding of women's responses to trauma such as domestic violence (Hillyer, 1993). The diagnosis of Multiple Sclerosis for example, is a difficult one to make, and finally being diagnosed (or 'labelled') provides at times relief from other labels of laziness, being 'neurotic' or psychologically unwell, and allows access to treatment. Labelling, under these circumstances can actually validate women's experiences (Lonsdale, 1990).

Zola reflects on disabling environments which impaired people face daily, as well as mainstream society's inability to access and communicate comfortably with (in a physical and psychological sense) impaired people. He relates these essentially 'personal' barriers to the broader political, social and economic structures which disempower disabled people. Those structures are underpinned by societal discourse, ideology and power.

In understanding the historical processes which allowed for the medicalisation of society, and in combining this with an analysis of power within the society within which disabled people live, a critical analysis of the social construction of disability and the disciplines and discourses which accompany it may occur.

OPPRESSION? THE SOCIAL MODEL OF DISABILITY

It is perhaps Michael Oliver's work that is most frequently associated with what has become known as the social model of disability, although others (Finkelstein, 1975, 1980, 1991; Abberley, 1987; Morris, 1989, 1991, 1992; Barnes, 1992; Chappell, 1992) have contributed to the critique of the ways in which society disables people.

Discourse, Ideology and Power

Len Barton (in Ballard, 1992) sees disability as a 'social and political category' which results in impaired people experiencing 'powerlessness and worthlessness in an alien society' organised 'by and for able-bodied males' (1992:15). Keith Ballard goes on to suggest however, that as 'oppressive ideologies and practices are 'social creations' rather than inevitable outcomes of impairment' (1992:15), they can be changed through political action.

In rejecting the medical model, and its discourse of disability as personal tragedy, the social model of disability proposes a new perspective. This discourse locates the cause of disability squarely within a society that imposes material, social, psychological and environmental constraints upon people as discrimination (Morris, 1991; Oliver, 1992) and social oppression. It is this oppression that 'disables' impaired people, it is therefore 'socially created' (Lloyd, 1992).

In redefining disability in this way, the distinctions between impairment and disability are drawn and defined, allowing the development of a new discourse and ideology which turns the spotlight on society and social organisation, shifting the focus from the personal (impairment) to the political (disability), and therefore places disability issues on the political agenda, 'demanding the attention of the policy makers' (Ballard, 1994:296).

By reconstructing disability as social oppression, the 'problem' of disability is viewed as being

located in the minds of able-bodied people, whether individually (prejudice) or collectively, through the manifestation of hostile attitudes and the enactment of social policies based upon a tragic view of disability (Oliver, 1990:83).

This approach therefore exposes the 'larger and more discomfoting truths' (Zola, 1977:62) hidden by the medicalisation of society, and develops an ideology that calls for social and political change.

Empowerment and Resistance: A Politics of Change

As already mentioned, Foucault argues that 'where there is power, there is resistance' (1979:96). The social model of disability, in utilising the understandings gained from the analyses of discourse, power, the medicalisation of society and the medical model of disability offers resistance at various levels.

At the level of the body, the rejection of the medical model challenges the invasion of disabled bodies which, within a Foucauldian analysis, become both the object of and subject to medical discourse, observation and examination (Foucault, 1973; Sullivan, 1996; Fassett & Gallagher, 1998). At the level of ideology we are able to challenge the discourses and language that attach disablist meanings to the disabled body as being deviant (Sarason & Doris, 1979; Lonsdale, 1990, Oliver, 1990; Hillyer, 1993; Haber, 1994) or 'inhuman' (Morris, 1991).

Within relationships, power can be identified and efforts made to alter power imbalances (Hillyer, 1993; Munford, 1995), and within communities and broader society, an oppositional politics of resistance (Haber, 1994) to the ways in which people and environments construct disability as social oppression can range from individual demands for equal treatment, access to buildings and public spaces (Oliver, 1990) to public protests and demonstrations (Morris, 1991) to effect change.

Politically the struggle involves ongoing critical analysis of the underpinning discourse that remains dominant in social policy today, through encouraging disabled people and their non-disabled allies to make the most of the 'windows of opportunity' (Barton, 1993) available to them to debate and contribute to challenging policy which fails to take into account their views and rights. This means engaging and participating as citizens of our society. Oliver (1990, 1996) argues that citizenship is a two way process. While demanding the rights of citizenship in terms of political, social and civil rights, we must also participate as citizens in order to place disability on the political agenda to be able to develop policy from the 'bottom up' (Williams, 1990).

The social model of disability has been critiqued from a variety of perspectives, including from disabled people. Oliver's *The Politics of Disablement* (1990) was criticised at times for being 'too academic' (Oliver, 1996) and therefore inaccessible to many disabled people. His response to this was to acknowledge that while he might not communicate his ideas as clearly as he could, he set forth the challenge that

If we are going to transform ourselves and society, it is only we as disabled people who can do the necessary work' (1996:2-3).

A further criticism of the social model of disability is that it tends to deny the physical experience of disability, and in so doing, can minimise the lived realities of being impaired (Morris, 1991; Georgeson, 1993, 1994). Morris for example argues:

We can therefore fall into the trap of trying to prove that our lives are worth living by denying that disability sometimes involves being ill, in pain, dying or generally experiencing a bloody awful time (1991:70), adding: there are negative aspects of being disabled which would persist regardless of the kind of society in which we live... (Ibid:70-71).

Sullivan also debates the need to relate the framework of the social model of disability to the 'corporeal experience of disability' (Sullivan & Munford, 1998:184), arguing:

For many disabled people their impairment has medical implications which compels them to adopt certain regimes of care without which the organism may deteriorate and die. These regimes might, in turn, require them to organise their lives around the care of their bodies. From this perspective, disability is not only the consequence of attitudes and the built environment, but also the subjective and practical experience of living an impaired body (Sullivan, 1996:4-5).

Abberley (1987), Lonsdale (1990) and Hillyer (1993) assert that the social model of disability denies the different subjective realities of different illnesses and impairments. Lonsdale argues that it denies in particular the downward trajectory of chronic, degenerative disease (1990:36-37) and this is certainly an issue in terms of this study, in that Multiple Sclerosis is not a static, stable disease, and neither are the impairments it causes. The very nature of MS suggests a tension between the social theory of disability and the lived reality of Multiple Sclerosis.

Lloyd, a feminist writer, contends that the discriminatory and exclusionary practices raised by the social model of disability are not confined to disability, but they are experienced by women anyway due to their gender (1992:210). Lloyd suggests a feminist model of disability, which focuses on gender and disability issues together, as does Morris (1991) who suggests:

The disability movement needs to take on the feminist principle that the personal is political, and in giving voice to such subjective experiences, assert the value of our lives. We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression (1991:183).

OPPRESSION? FEMINISM AND DISABILITY

Discourse, Ideology and Power

Feminist approaches vary, but generally focus upon a political analysis of the structures of society as being patriarchal in nature and oppressive to women. Such an analysis argues that societal structures are created and maintained by men in the interests of men and fail to take into account the needs of women, or defines their needs from a male perspective.

The concept of power is therefore a central concern within such an analysis (Van den Berg & Cooper, 1986), as are issues of women 'naming' their own experience on their own terms. A key tenet of feminist thought is that the personal experience is political (Ibid:7-10) and that personal troubles are linked to political or public issues (Craig, 1988:11). Inherent in this is the commitment to the elimination of discrimination and oppression; through active participation, self determination and empowerment at a personal and societal level (Craig, 1988).

However, just as the social model of disability has been criticised for failing to address adequately the issues of women's lived experiences of disability, so too has feminism been critiqued for its failure to address adequately the issues of gender and disability (Morris, 1991; Lloyd, 1992; Hillyer, 1993). Lloyd asserts that the women's movement **and** the disabled people's movement have not taken disabled women's concerns on board, and argues that the multiple inequalities experienced by women result in them having to create a hierarchy of inequalities, with one or other taking priority (1992:208). Morris argues that feminism has ignored disability and old age as two areas of life in which gender is a key issue (1991:7), and suggests that feminists must re-examine the ways in which societal attitudes towards disabled people are reflected in the feminist movement.

Discourses frequently discussed from a feminist analysis of disability include key issues around the 'invisibility' of disabled women (Lonsdale, 1990), what happens to disabled women's bodies (Blackford, 1993; Wendell, 1993), already identified as a 'site of struggle' (Munford, 1995:38) and the bodily experience of disability. This includes frequent references to the concept of 'passing' (Morris, 1991; Hillyer, 1993; Wendell, 1993) or hiding disability (Stone, 1993) in order to be accepted in society at large - often at great personal, psychological and physical cost (Hillyer, 1993). The dependence / independence dichotomy and the issue of 'care' (Morris, 1991; Hillyer, 1993; Georgeson, 1993, 1994; Munford, 1994b; Opie, 1995) is frequently raised within this perspective, as are issues of socially and culturally constructed concepts of 'time' (Hillyer, 1993), including the time spent 'waiting' (Munford, 1992, 1994b, 1998) and the links between 'time', 'work' and 'productivity' (Davoud & Kettle, 1980; Lonsdale, 1990; Hillyer, 1993). These issues will be discussed in greater depth in Chapter Seven of this thesis in terms of their relationship to the experiences of the women in this study.

Empowerment and Resistance: A Politics of Difference

While none of the above writers reject the social model of disability in its entirety, all of them suggest adaptation of the model to include the more specific issues discussed above. Still others suggest developing further a 'politics of difference' (Sawicki, 1991; Georgeson, 1994; Haber, 1994; Kerr, 1994) based upon the recognition of women holding 'multiple subject positions' (Kondo, 1990; Sawicki, 1991) or different 'identities' (Haber, 1994) which allow for the recognition and celebration of difference.

A politics of difference begins with an analysis of how 'other' (as women, as disabled people) is constructed within 'normalising power regimes'. Haber suggests that a politics of difference begins with:

Self respect and self knowledge among individuals whose identity has either been silenced, devalued or erased altogether because they belong to some group whose value is denied by the ideology of the controlling social powers (1994:124).

In order to do this, she suggests:

To value ourselves we must learn to recognise the different identities that exist not just in society at large, but in each one of us as well... recognising oneself in a variety of communities plays a large part in the process of self identification and in the process of empowerment. Community identification is necessary to self identification, and both are necessary to any politics of difference (1994:125).

An oppositional politics, argues Haber, needs to 'accommodate both difference and similarity' in order to challenge the 'sovereignty of normalising and disciplinary discourse' (1994:134).

Sawicki's analysis of multiple identity or subject positions rejects somewhat Lloyd's (1992) suggestion of a hierarchy of multiple inequalities. Sawicki (1991) undertakes a Foucauldian analysis of disability and feminism, and rejects the concept of a central identity either as a woman or as disabled, arguing that instead, a number of different 'identities' exist in any one personality, which 'combine and re-coalesce in different ways, at different times and in different contexts' (Wicks, 1996:4). Such an analysis within a Foucauldian perspective allows the development of an understanding of the 'multiple centres of power confronting multiple centres of resistance' (Kerr, 1994:83) and 'prompts us to look for the diverse relationships that women occupy in relation to these technologies and for the many intersecting subject positions constituting the subject field' (Sawicki, 1991:87).

The concept of multiple subject positions is particularly intriguing in terms of living with Multiple Sclerosis. On any given day, subject positions for people with MS may change, depending on what impact the disease is having on the body that day. While this is discussed in greater detail in Chapter Seven, the discussion above suggests a vibrant complexity which, while changeable, is already an integrated whole. In such a position, recognition of difference as well as similarities between subject positions can allow for the development of a politics of difference, in which the lived experiences of women **and** of disability are heard, acknowledged and utilised within a politics of change.

If the lived experiences of disability, positive and negative, are valued as important facets of an important whole, then, as Morris writes:

I can therefore value my disability, while not denying the difficulties associated with it... If we feel strong enough to do this, we can truly challenge the way non-disabled people make judgements about our lives, because in so doing we will take charge of the way in which disability is defined (1991:71).

MULTIPLE CHOICE? POLICY ISSUES IN AOTEAROA NEW ZEALAND

If one utilises the tools of analysis offered by a Foucauldian perspective, the social model of disability and feminist thought, then, as already discussed, the focus of disability as a 'problem' shifts from being located within an individual to residing within the discourses, practices and ideologies of a society which supports and maintains positions of power in some groups, and positions of marginalisation in others. As already mentioned, discourse exists at all levels of society - from the internalised discourse of the 'disciplined individual' (Foucault, 1977b) to the socially constructed and determined political discourse of a given society.

Within Aotearoa New Zealand, the political discourse that has been dominant, particularly since the election of the Fourth Labour Government in 1984 has been that of economic liberalism and a reduction in state spending (Perkins, 1994). However, at that time (1984), while benefit levels fell for most welfare recipients, those of sickness and invalids beneficiaries rose, from the consideration that this group (sick and permanently disabled) were 'incapable' (Shannon, 1991) of self-help and therefore needed welfare assistance.

This subject position as 'other' (that is, an identified group 'different' to welfare recipients in general), while perhaps benefiting economically at the time (compared to those on unemployment and domestic purposes benefits) did little to encourage acceptance of sick and impaired people within their communities. This in part was due to the unanticipated outcome of a significant shift of long term unemployed to sickness benefits, which resulted in many sick and impaired people being considered to be 'faking' their illnesses to obtain a higher benefit.

Since the Fourth Labour Government, this subject position has been 'restructured' (Sullivan & Munford, 1998) beyond recognition; as successive government policies have clawed back the welfare state by imposing more and more rigidly defined criteria for people to meet in order to obtain assistance. This has been to the detriment of the most vulnerable in society, particularly women and disabled people. The rolling back of the welfare state has led to a different subject position - from 'incapable' (but supported by welfare provision), to 'consumer' (with little to spend).

All too often, disabled people come under the 'gaze' (Foucault, 1973) of the health, welfare and education systems. In order to receive services from these

systems we are required to undergo numerous examinations - to identify how 'different' we are in relation to the 'norms' of society and to each other and to establish whether or not we are able to 'conform'. As discourse has changed over the past sixteen years to that of economic liberalism, our non-conformity has become couched in terms of the economic marketplace - ironic libertarian terminology which has not, to date, provided what it proposes.

A number of social policy and social work writers have contributed critiques to the discourses of current social policy in this country. Munford (1992, 1994b, 1995, 1998) raised numerous questions in 1992 as to the likely impact on caregivers and disabled people of the policy document titled *Support for Independence* (Shiple & Upton, 1992). In 1992, Munford expressed concerns that, while couched in the libertarian discourse which espoused 'freedom', 'choice', and 'family' or 'community', this document may result in the further marginalisation of disabled people as 'objects' under the Department of Health, lose 'choice' as decision making would be in the hands of professionals as to what supports they would be 'entitled' to; and raised important questions around what supports would be provided to 'family' or 'community' in the provision of care.

When reading Munford's successive critiques, these issues are raised repeatedly, and a pattern emerges which reveals that her concerns of 1992 have been more than realised. Boyles (1994) also critiques the *Support for Independence* document, arguing that the submissions made against it were 'largely ignored' (1994:10), adding that the content of the Health and Disability Services Act (1993) evidenced that the 'consultation' process of the *Support for Independence* document had been a 'token gesture to an increasingly vocal disability community' (Ibid:10). Similarly, Perkins (1994) raised concerns as to the likely impact of this policy document as well as the unintended

consequences of 'normalisation' and deinstitutionalisation of intellectually impaired people, particularly those with challenging behaviours. Her concerns are echoed by Thompson and Anderson (1996), and Thomson (1998).

While conceding some positive outcomes for intellectually impaired people in terms of the Human Rights Act (1993) and changes in the 1992 Mental Health (Compulsory Assessment and Treatment) Act removing the threat of compulsory institutionalisation due to intellectual impairment alone, Thompson and Anderson caution that community based services could again turn full circle. That is, their concern is that reducing resources could place such pressure on families and communities that they are no longer able to provide care to the degree that re-institutionalisation could result. Their concerns were not unreasonable, given that Brown (1996) writes of the ways in which government has eroded choices for families who care for disabled children by ring fencing respite care budgets and reducing respite options, and she exposes the beginnings of a fracturing health / welfare system.

The impact upon families has begun to be exposed, this was particularly evident when, in the late 1990s, Janine Aubrey-Thompson went to jail for murdering her Autistic daughter Casey as she could no longer manage her daughter's challenging behaviour and was unable to access respite care. This issue is also debated further in Chapter Nine of this thesis, where the last five years of Ruth's life are presented, which identify her and her husband's struggles with her increasing needs and decreasing assistance as her life with Multiple Sclerosis ended.

Keith Ballard presents similar concerns in his analysis of the education system providing fragmented services to impaired children and describes educational policy which segregates based on medicalised constructs of individual

pathology (1992:17). He argues that by identifying disability as a 'personal trouble', the education system denies its responsibilities for disabled children (Ibid:17).

While the advent of the Human Rights Act (1993) in theory finally acknowledged disabled people as 'being human' (Sullivan, 1998:375), on testing, it was perceived as 'having holes in it big enough to drive a lorry through' (Ibid:375). Upon being tested on equal access to public transport (Beadle, 1995), the Act was exposed as being fundamentally flawed and weak (1995:109) and, as a consequence, Beadle asserts that the civil rights of disabled people are negotiable (Ibid:104).

This has significant implications for disabled people in all areas of life, as New Right policies impact significantly on welfare benefit provision which has been significantly reduced, state housing rentals (which until this year's changes by the Labour government stood at market rates), health provisions (often considered too little too late - or alternatively too little too cheap) and in terms of work. The 'reasonable accommodation' clause of the Human Rights Act 1993 provides an easy option 'out' for employers, service providers and the state alike. It reduces disability again to being a problem located within an individual rather than ensuring (or even encouraging) societal change to disabling environments.

Wolfensberger (1989) suggests that the true purpose of social policy is to maintain the economy, enhance the power of the privileged and, as a consequence, to reject, exclude and punish disabled people, but in a disguised way which appears acceptable. The 'disguise' of current social policy in this country is the language of economic liberalism - policy documents are couched in terms of the disabled person having individual 'choice', of an increase in

'consumer power' by shopping for the services and commodities they require in order to best live their impairment as 'independence'.

The lived realities of the 'consumers' of the health and welfare systems are more frequently a reduction in or lack of choice (Munford, 1995), little or no spending power as a consequence of reduced and capped budgets, and increasing dependence. Successive National governments from 1990 to 1999 moved to 'roll back' the welfare state, developing a residualist approach (Thompson & Anderson, 1996) to welfare provision and a 'modest safety net' for those unable to meet their basic needs.

The concept of a 'safety net' is an interesting one. In circus high-wire and trapeze acts, a safety net provides an obvious mechanism by which a performer, should they fall, is prevented from death or injury. If the net is strung too loosely, they will plummet to the ground. But, just as important, if the net is strung too tightly, they will bounce off it, to *then* crash. Alternatively, the net may be so taut that it will not take the impact, and instead splits, with the same effect. It is my contention that the New Right 'safety net' has become tighter and tighter - as a consequence, more and more people are bouncing off or falling through it, with devastating consequences.

CONCLUSION

This review has attempted to draw together a number of complex theoretical constructs in order to inform the reader of the theoretical underpinnings of this research. The overview of the concepts of discourse, knowledge and power introduces a Foucauldian perspective, and is followed by an historical analysis of Zola's medicalisation of society, which is followed by an introduction to the social model of disability. Leading on from this model is an overview of the feminist analysis of disability, which develops further the concept that disability

is a form of social oppression underpinned by discourse and ideology and maintained through power. Each of these perspectives is developed further in the results and discussion section in terms of their applicability to the experiences of the research participants, so are, as yet, incomplete.

While each writer discussed so far has different perspectives on the experience of disability, each, despite these differences reveals a similar concern: that of the lived experiences of disability. Each writer contributes a piece of an ever changing puzzle of lived realities for disabled people, and each, in their own way, presents resistance and change as an opportunity. The lived experience of disability is also the concern of this study, and the literature presented underpins the methodology and research paradigms undertaken. It is to the research methods and design of this study that I will now turn.

CHAPTER THREE: RESEARCH METHODOLOGY AND DESIGN

THE PERSONAL IS PERSONAL

As the news was revealed, a profound and sudden sense of shock pierced through me. My world seemed to fall away from under me, taking with it all the hopes and dreams I'd held dear to me for the past four years. Those dreams that had nourished and sustained me over some of the most difficult times of my life shattered about me, and evaporated into an increasingly dark void. I felt totally paralysed, immobilised by this news, unable to take any action, unable to sense anything other than an icy cold spreading panic and loss. As my surroundings became dark, somewhere in my panic the voice of reason reminded me to breathe. I gulped in a lungful of air and with that my vision cleared. With that too, came tears. But the sense of paralysis remained for several days. The paralysis of oppression, more profound, more insidious, more disabling than anything this disease had, to date, thrown at me. (S. Green, personal reflection, July 2000).

INTRODUCTION

This chapter aims to serve a number of purposes. The primary aim is to inform the reader of how this study was designed and carried out - inherent in this is the opportunity for others to critique the approaches taken and the methodological underpinnings which informed my approach.

Additionally however, this chapter aims to also document the process of bringing together all the steps taken to complete this thesis. Finally, this chapter describes an experience of oppression I as a researcher faced prior to conducting the data collection for this study. This experience prompted the reflection written above, and this chapter also forms the beginnings of my response to that experience of oppression.

RESEARCH METHODOLOGY

A Qualitative Research Design

The primary methods used to conduct this research were those of in depth interviewing and participant observation, with content analysis of written records used as a secondary method. Denzin defines Participant-Observation as combining survey-interviewing, document analysis, direct observation and observer-participation (1989:234), with a central assumption that the researcher shares as 'intimately as possible' the life, social activities, language and establishes a 'role' for themselves within the community they are studying (Denzin, 1970:187). Kerr adds to this by stating (as a parent / researcher):

There was no need for me to learn a new language... in order to share in the symbolic world of the participants. I already know the language - it is the language of disability, the language of exclusion or inclusion, the language of medicalisation, the language of professional mystification, the language of failure, success, tears and joy (1998:17).

As a disabled researcher, I too recognised that I already knew the language of the symbolic world of living Multiple Sclerosis - that while the 'dialects' of my own and the participants' discourses may at times be different, the world we shared was in a multitude of ways very similar.

Beginning with the personal narratives of the research participants, in depth interviewing moves towards a "descriptive understanding" (Tolich & Davidson, 1999:32) of the narrated data. It is therefore an inductive qualitative research method, and one which can be used either to contribute to the development of theory (Bulmer, 1979) - as is intended in this study, or towards further research design (both qualitative and quantitative), structure and interpretation (Sieber, 1973).

Qualitative schools of thought argue that human action is a consequence of complex interactions and relationships between worldviews, values, language and meaning making which is socially and culturally constructed within a given time and space (Tolich & Davidson, 1999: 24 - 30). Consequently, science is also considered to be socially constructed and can therefore not define or explain reality in the reductionist form undertaken by a quantitative paradigm. This positivist paradigm seeks to claim a universal 'truth' through careful measurement of observable data.

The use of observation and in depth interviewing within the qualitative paradigm allows the researcher to seek out the meaning people attribute to their experiences (Tolich & Davidson, 1999:30) as they live them, which makes it an appropriate choice for researching the lived experiences of women with Multiple Sclerosis. Inherent in this approach are some of the strengths of this method - those of access to a great breadth and depth of information from which meaning making emerges.

Lost in the shuffle: Research as social oppression

My initial searches for academic research on the lived experiences of women with Multiple Sclerosis revealed a vast array of quantitative studies on a variety of aspects of the disease itself, from personality, patient attitude and adjustment to the disease (for example, Halligan & Reznikoff, 1985; Antonak & Livneh, 1995; Evers & Karnilowicz, 1996; Barnwell & Kavanagh, 1997), to psychiatric co-morbidity, emotional and cognitive changes (including Schiffer et.al., 1983; McIvor et.al., 1984; Halligan et.al., 1988 and Rao et.al., 1992), as well as physical and psychosocial functioning (Decker & Decker, 1994). Without exception these studies individualised disability as an inevitable consequence of the disease, and failed to describe my own lived experience of disability as social oppression.

A few academic studies were located on MS and the use of personal narrative in the presentation of self (for example Riessman, 1990; Robinson, 1990). Perry (1994) is a particularly good example of such an approach, but very few (for example Simons, 1984; Dyck, 1995 and Barrett, 1995) came anywhere near suggesting that the nature of society disables. The stories of people with Multiple Sclerosis remained on the fringes and seemed lost in the academic shuffle. Oliver (1992:105) argues that the above forms of research alienate disabled research subjects and fail to adequately represent their experience, let alone their needs.

All of the above studies focused on the general population with Multiple Sclerosis, and very few analysed the experiences of women with the disease separate to men. Given that women get MS at a much higher rate than men, this was disconcerting. Until early in the year 2000, I was unable to locate any studies which focused on the personal narratives of women with MS from a feminist perspective.

Fortunately that has changed, with Hightet (1999) presenting a Master of Social Work thesis in which the narratives of womens' experiences of Multiple Sclerosis form the basis of her feminist analysis of disability. Hightet's use of participant observation and in depth interviewing allows the experiences of women with MS to be presented and heard, 'illuminating connections between biography, history and social structure' (Rheinhardt, 1992:131). In obtaining the depth and richness of information afforded by this method, it is possible to more fully record not only the experiences of the research participants, but also their insights into the meanings they have given these experiences. For the purposes of this study, the meaning making process was a crucial part of my analysis of how the discourse of the medical model or patriarchal thought is internalised, information unlikely to be gained through quantitative methods.

Storytelling from the Margins

In utilising participants' own narratives and their own understandings, realities and truths about the world they live in, researchers can allow for a 'restorying' of in particular, those groups previously marginalised by the application of 'science' underpinned by eurocentric, disablist or patriarchal thought. Feminist (for example Oakley, 1981; Smith & Noble-Spruell, 1986; Stanley & Wise, 1990; Jayaratne & Stewart, 1991) as well as disabled researchers (including Finkelstein, 1980; Oliver, 1990, 1992 and Morris, 1992) have challenged the 'truth' of the positivist paradigm of science by utilising qualitative and emancipatory research paradigms. Such use is focusing on the importance of storytelling (Ballard, 1994:24) to allow the emergence of new narratives from the margins. From these stories of lived lives and the meaning attributed to them by those living them, new theory is being developed which is beginning to validate some of the alternative 'truths' proposed by post modern thought.

The purpose of this research then, is not to claim a new scientific 'truth' in terms of the positivist paradigm, but to contribute to the expression and validation of the lived realities of impairment and disability from the margins; to critique new theory and to contribute to the continued development of emancipatory research paradigms.

A Paradigm Shift: Emancipatory Research

Both feminist and disabled researchers emphasise a paradigm shift in terms of the development of research models which not only meet the needs of the individuals involved, but which also link the research to the policy making process, with the intent of effecting positive change for the research subjects. Within the field of disability research, the emancipatory research paradigm emerged from a 'critical model' of disability (Bennie, 1998) in which disability is

perceived as a political problem rather than as a medical (scientific model) or social (interpretive model) problem.

Within a critical perspective (Fay, 1987), the social world is perceived as being structured in such a way as to ensure the maintenance of the interests of dominant individuals or groups, and is maintained through discourse, ideology and power at all levels of society, including within the research arena. Research legitimates knowledge as a source of power, and those involved in the production of knowledge are considered powerful in society (Wight-Felske, 1990; Roeher Institute, 1991).

Until relatively recently, social research has been dominated by the positivist or latterly, the interpretive paradigms which Boyles argues 'have not contributed anything to change the daily lived experiences of disabled people' (1994:7). An emancipatory research paradigm seeks to instead challenge the structures of society which maintain an individual or group in a position of marginalisation, to offer options for empowerment and make use of opportunities for change at all levels of society.

In so doing, the very nature of knowledge production is called into question. In this, emancipatory research seeks to develop a more reciprocal empowering relationship between researcher and researched (Boyles, 1995; Perkins, 1998) in which mutual gain occurs. It seeks to establish what research methods best allow such a relationship to occur, and to propose a structure within which researchers must work to ensure that the production of knowledge about vulnerable or oppressed people is constructed in such a way as to create gain for the participants of the research process.

This paradigm is not new, it has also been presented in terms of feminist research (Jayaratne & Stewart, 1991) based upon mutual trust and reciprocity (Oakley, 1981), collaboration and leading to action and social change (Smith & Noble - Spruell, 1986). Emancipatory research demands that one 'start from the experience of the researcher, who must be prepared to make herself as vulnerable as those being researched' (Smith & Noble - Spruell, 1986:141). In locating myself as a feminist researcher, who lives daily with the disease Multiple Sclerosis, my experiences expose me as frequently as those of the participants to the oppressive discourses of patriarchy and disability. In this, I am at times as vulnerable as they are, and in this, their narratives and my own are intertwined.

And yet, my role as a researcher committed to an emancipatory paradigm carries with it a burden of care and calls for reflexive practice in order to not make assumptions that the intertwining of the narratives of researcher and research participants means we are the same. Kerr (1998) discusses the need for identifying, respecting and representing the differences between herself as a researcher and the participants, and between participants themselves. This was of particular importance to her in her dual subject identification as both professional and participant; and represented a significant challenge to myself as a participant (a woman with MS) and observer (as a researcher).

While seeking the personal expertise of the research participants, I became at times acutely aware of the imbalance in power relations between us; a sense of that which until then, I had only read about. To address that imbalance somewhat I undertook to honestly answer questions the participants had of myself and my own experiences when they were asked, (Lang, 1994), and at the completion of my involvement with them, I attached a copy of my own narrative (Attached as Appendix Three) to the research summaries I sent to

them. In doing so, I exposed myself to becoming in many ways as vulnerable as they did - I have as little control over what they choose to do with my narrative as they may have felt about my knowledge of them.

In constructing the research design for this study, I undertook to follow as closely as possible the emancipatory research paradigms recommended by writers such as Oliver (1992), Boyles (1994, 1995, 1997), Perkins (1998) in order to address some of the issues discussed above.

Any social research design is influenced by a myriad of forces which impact upon the researcher before they even begin to study the social event, problem, policy or topic they select. Likewise, the outcomes of their research are similarly influenced - for these and other reasons, research as a whole may be said to be socially constructed (Stanley, 1990; Boyles, 1994). For these reasons also, it may be suggested that no research design can ever be 'perfect' (Denzin, 1989), even positivist, quantitative research designs are influenced by societal discourses as is previously discussed.

The first chapter of this thesis outlines the aims and aspirations of this enterprise, the background from which my interest in this study developed; the value base I come from, the experiences which formed the research questions. Locating myself from this background, and drawing on my knowledge base, both medical and academic, the following research design was developed.

RESEARCH DESIGN

The Research Question

The purpose of this research is to study the lived experiences of women diagnosed with Multiple Sclerosis. The intent of the study was to discover whether or not their experiences supported or refuted the theory that disability

is a form of oppression arising from the discourses of power, patriarchy and the medicalisation of society. Essentially therefore, my approach has been to apply the data obtained to established theory, an inductive strategy (Patton, 1990).

The research questions for this study are:

Does a combination of patriarchal discourse and the medicalisation of disability oppress and exclude women with Multiple Sclerosis from society, thereby reducing their options in life more than their progressive impairment?

and stemming from this -

Do the alternative discourses of feminism and the social model of disability offer women with Multiple Sclerosis options for politicising their experiences and opportunities for empowerment and emancipation as a consequence?

Units of Analysis

Sample Size

Given that this study is a qualitative inquiry, the sample size was designed to be a relatively small number of 'information rich' (Patton, 1990:169) cases. Within each of two selected locations, between ten and fifteen women were to be interviewed within a focus group interview, and from the two groups, four to six women would be selected to participate further in individual interviews. This study therefore, would not claim to be representative of all womens' experiences of Multiple Sclerosis, but **could** have provided a solid basis upon which to further explore the issues raised within the interview settings.

Sample Structure

Assistance was to have been sought from women participants from two discreet areas of Aotearoa New Zealand, comprising one large city and one rural area

located in the North Island. The purpose of these locations was to gain an appreciation of whether living in a city or smaller community altered significantly the reported experiences of the women interviewed. The sole reason for not including the South Island was due to financial constraints.

Sample Selection

Following selection of the two locations for this research, contact was to have been made with the Field Officers of the Multiple Sclerosis Society in each region. The Field Officers were to be asked to approach all women in their region who had been diagnosed two years or longer and invite them to participate in a focus group interview for this study. The purpose of this approach was to ensure the privacy of prospective participants. Any disadvantages accrued by this approach (lack of rigor in participant selection) I believed would be outweighed by the fact that until participants consented to participation in this study, I would not be aware of who they were.

Women diagnosed for less than two years were excluded from this study for two reasons. Firstly it is a time during which people diagnosed with MS are adjusting to the diagnosis and discovering how the disease will manifest itself. Secondly, it is rare for significant permanent impairment to be present within this length of time.

Also excluded from this study were women from my own region. As a member of my local MS Society, to include women from my own area represented a conflict of interest. While I am indebted to the women of my region for their contributions to the formulation of my research, the information they gave me was shared within a different context and not solicited for the purposes of this research.

At the focus group interview, the women attending were to have been asked to indicate whether or not they also wished to participate in an individual interview. Where more women volunteered than I was able to interview, final selection would have been made to cover as broad an experience base as possible.

The Process of the Research Design

This process was developed over a lengthy period of time, and in consultation with the National MS Society Office. An initial call was made to the office towards the latter half of 1999 as I was preparing to submit my research proposal to the University. I discussed at some length what I intended to focus on, and this initial contact was met with a supportive response, including the encouragement to *'tell the stories of women with MS'*.

Any research involving human participants at Massey University is subject to approval from the University Ethics Committee. While preparing my protocol for the Ethics Committee I again contacted the National MS Society (In March 2000) and discussed the proposed research. By this point in time, I had tentatively selected the research locations. I continued to meet with a positive response, and was in fact posted the names of the Society Field Officers of those locations two days later. Having had my approach confirmed, I submitted my protocol to the Massey University Ethics Committee. A copy of the full protocol submitted is attached as Appendix One of this thesis.

Problems

The Ethics Committee approved the protocol with a few amendments to be made, one of which being that they received written confirmation of approval from the National Multiple Sclerosis Society. I made further phone contact on 3 July 2000 with the National Society and Dr M., the Director of Research and

was told to present my information to the Society's Research and Advisory Committee which was meeting the following week. I faxed a copy of my ethics protocol the following day, attaching contact numbers in order that the Committee was able to contact me should they have any questions.

Three weeks later I had not heard anything, so phoned the National Office and left a message asking that I be advised of the outcome. On the evening of 26 July 2000, I opened an e-mail from the National Society which advised that the Committee had decided not to support my study - and that I would shortly receive a letter outlining the reasons for this. It was this piece of news, and that which followed below, that paralysed me at the beginning of this chapter, a paralysis that for me was more profound than the physical paralysis which Multiple Sclerosis had inflicted on me in previous years.

“Not your kind of research...” The false dichotomy of the positivist paradigm

The following day, I made numerous phone calls to various people at the National Society. My first call was to the woman I had initially contacted. Her response was that she *'couldn't understand why it would be refused...'* that they *'have lots of students who access people with MS... most of whom are not at this level..'* [of studies]. She suggested I make further contact with Dr. M. which I did immediately. During the brief conversation that followed, which was witnessed, he made the following comments:

The group did not support the concept... this was not a scientific, hypothesis - driven piece of research... it was felt that the outcome of the research was self - fulfilling and predictable...

At first somewhat puzzled, I recognised with a degree of shock that the very discourse I was hearing was that which is critiqued within the literature review

and the methodology section of this chapter - and I suggested this to him. His response was (perhaps predictably) defensive, responding that

the committee doesn't only consist of crusty old white haired men... but also women and women with MS who also didn't support this...

To ascertain how they might have reached this conclusion, I made an attempt at discussing how patriarchal and medical model discourse can be internalised by women as well. I also endeavoured to discuss with him the comment he made about the outcome being predictable. Dr. M. seemed 'lost' when I outlined how I expected the social model of disability might be tested. Given that the Director of Research did not, it appeared, have an actual understanding of the theory involved, then I realised that the decision must have been made on the basis of the very concepts of this study being too threatening for them to face. I suggested this, and he began to bluster somewhat.

Finally, I asked him to be explicit about what type of research the committee wanted. His response by now was utterly predictable: "*We want hypothesis - driven quantitative studies*". He then advised that Dr W. who headed the committee would be writing to me and gave me a contact address. After sending a fax and a letter, I finally received the following e-mail on 9 August 2000.

Dear Ms Green: I agreed to summarise the views of the MS Society Advisory and Research Committee in declining support for your research proposal ... The background is that, in recent years, we have supported a number of research projects that have addressed different aspects of the impact of the disease on persons with MS and their families. Most have concentrated on psychological and social effects of disability and have made use of interviews with persons with MS and their families. Concern has been expressed that considerable demands have been made on persons taking part,

when the scientific rigour of some of the projects has been doubtful and the results of limited value. It has been emphasised that, to maintain goodwill from persons with MS who are prepared to contribute, we should look carefully at the scientific basis for such studies. The main concern with your project was its uncertain scientific basis. It was felt that its thrust and structure was aimed at finding support for a politically pre-determined point of view of impairment and disability rather than an objective assessment of a complex issue. The concept that women with MS are more disabled by 'patriarchal discourse and the medical model of disability' than by the effects of the disease is certainly controversial and would need as objective an approach as possible to produce interpretable results. For instance, it is not at all clear how your hypothesis relates to disability in men with MS - should they be included as a control group? In this sort of study, the basis for selection of the limited number of persons interviewed is also important. We did not feel comfortable supporting the project as it was presented...

What this response, and that in my phone call to Dr. M. did, was exposed to me the degree to which a section of the Society **of which I was a member** was threatened by the very theories I was evaluating; their responses actually confirmed in many ways the debates and arguments outlined later in this study. The 'false dichotomy' (Wallace, 1971; Louis, 1982) between positivist and interpretivist epistemologies exists it seems, in a very real way within the Research and Advisory committee of the National MS Society of New Zealand.

By the time I received this e-mail, I knew what the response would be; in terms of both a feminist analysis and in looking at the analyses of disability research undertaken by Finkelstein (1975, 1980) and Oliver (1992) this was a 'classic' response to the threat of disabled people naming their own worlds and the possibility of their empowerment. As Finkelstein (1975) writes:

We have noticed that it has always been others who have researched, written and analysed, examined our history, and proposed their knowing solutions for us... Can it be that having others research on the lives of disabled people (rather than us expressing our own experience) has something to do with the very nature of disability?

While this response stopped me in my tracks for a short period of time, perhaps the most important aspect of it was that it made the decision on behalf of women with MS - thus removing any **choice** they may have had to decide whether or not to participate, and therefore potentially silencing them.

Reflexive Evaluation

Having one's research accused of being unscientific and "*having a thrust and structure... aimed at finding support for a politically pre-determined view... rather than an objective assessment of a complex issue...*" **before** it has even begun forced me to seriously re-think the entire basis of my research design and methodology. This was not necessarily a bad thing to do - although I had expected to be doing it **after** the research was completed, as this thesis would then be available for critique!

What it meant was that I conducted a rigorous reflexive (Wicks & Terrell, 1992; Boyles, 1994; Lunn, 1998) evaluation of my knowledge base, my reasons for undertaking this research and of the ways in which I planned to go about it. It meant consulting further with others, including people with Multiple Sclerosis and their families, my own local Field Officer, and medical people and academics who used both quantitative and qualitative research paradigms.

The overwhelming feedback I obtained was that this research should continue. Three of the women with Multiple Sclerosis who I spoke to wanted to know why they were not asked by the organisation before the decision was made; my colleagues who have conducted qualitative research felt that the decision was not ethically justified in that while the Committee could have declined to support the study on ethical grounds, no such grounds existed in this case - that any decision regarding maintaining the support of people prepared to participate should be made by participants themselves.

Medical colleagues felt that the decision reflected a 'bias' towards the positivist paradigm which, in their opinion was not an adequate reason to prevent the research continuing and countered that more research of this type could assist in developing better models of medical research and medical practice.

Finally, a fellow medical researcher who utilised both qualitative and quantitative paradigms in practice critiqued my approach, and while suggesting that a broader quantitative study in addition to what I proposed would strengthen the study in terms of generalisability, she could see no reason, ethically or academically why this study should not be supported. She acknowledged that the theories under critique were controversial, but felt that the research questions were clear that I was questioning those theories, not that I was attempting to find support for a politically predetermined view. With this feedback in mind, the research design was amended to the following approach.

AMENDED RESEARCH DESIGN

The research questions and concept definitions remained the same. The two research questions are **not** a pre-determined political agenda. I wanted to discover if the experiences of the women I interviewed did support or refute (in all their complex nature) the theory that disability and patriarchal discourse could oppress women more than their progressive impairment. The aim of asking these questions of the theory was not to 'prove' or 'disprove' one theory or another, but to conduct a genuine inquiry - and in doing so, contribute further to the academic debates around the social model of disability and feminist discourse.

Sample Size

This study remained a qualitative inquiry, and the sample size remained a small number of purposefully selected (Patton, 1990) 'information rich' cases. Due to the length of time that had elapsed while waiting for a response from the National MS Society, I had to eliminate the initial focus group interview from the research design which reduced the number of participants I was able to interview. My focus had to shift to individual interviews.

Sample Structure

The exclusions of women diagnosed less than two years, and women from my own region remained the same, for the same reasons. Assistance was sought from women participants via three advertisements placed in two newspapers in the North Island of Aotearoa New Zealand. These newspapers had a broad coverage of both rural areas and at least one large city in the North Island. Additionally, a copy of the advertisement was sent to General Practitioners and health providers in the region, along with a request that these be displayed in their waiting areas.

Women were able to make contact with me by using a freephone number, either to enquire about the research, or to request an Information Sheet and Consent Forms. Once these were sent, no further contact was made by myself until Consent Forms were received back from participants. In the event of more women agreeing to participate than I was able to interview, participants were advised in the Information Sheet that final selection would be made to cover as broad a range of experience as possible. That is, where possible, selection included:

- A variety of age groups - to gain an appreciation of the ways in which societal reactions to impairment may have changed according to cohort.
- Differing lengths of time since diagnosis was made.

- A variety of levels of impairment - to compare the experiences of those with 'invisible' impairments (for example fatigue) with those whose impairment is more obvious (for example, a wheelchair user) as well as to gain an understanding of how society has reacted to their increasing levels of impairment over time.
- Women who are in paid employment as well as those who are not, or who are in part time employment.

The purpose of such a selection process was to draw from an initial homogenous sample a final, stratified sample which could best represent 'above average, average and below average cases' (Patton, 1990:174) in order to enhance the probability of capturing variations in the responses rather than to fit a sample most likely to support a politically pre-determined view. Had my intention been to make use of operational construct sampling, I would have been at pains to select women using very different criteria.

As it transpired, further sample selection was not required. From fifteen initial enquiries, eleven participants returned consent forms. One of the initial enquiries was from the South Island, and was informed that this research was limited to North Island participants. Due to time constraints, three late responses from participants were not able to be pursued.

Ethical Issues

Within any research involving human participants, a number of ethical issues must be addressed. Consideration must be made regarding the process of consent, issues of privacy and of ensuring adequate support is made available to participants during and/or following contact with the researcher. While these issues are discussed fully in the attached copy of my Massey University Ethics

Protocol (Appendix One), the following steps were taken to address these issues:

- **Consent.** Prior to making further contact with any person who had requested information about this study, I received a signed Consent from them. The Consent form was attached to an Information Sheet which outlined the study I was undertaking, the rights of the participants to ask questions at any time and have them answered, the right to refuse to answer any question and the right to withdraw at any time. Also covered were their rights to a support person and to consent to interviews being audiotaped. This included the right to have recording equipment turned off at any time.
- **Privacy** Participants were advised within the Information Sheet as to the ways in which their information would be collected and used, the storage and treatment of their information and the right to have information returned immediately should they choose to withdraw from the study. Participants were also informed of their rights to see and correct any of the information obtained. Transcripts of taped interviews and copies of my fieldnotes were sent to the participants to check for accuracy and to correct. Participants were advised that the presentation of their information would be in summarised form to protect privacy and reduce the chances of them being identified as a participant. Additionally, participants were encouraged to choose an 'alias' to further protect their identity within the reported data.
- **Support** Participants were encouraged to have available a support person during and following an interview. Information Sheets and Consent forms were also created for support people which outlined their rights within this study (see Appendix One). Every endeavour was made to ensure that

participants were not left in a distressed state by the interviewing process. All of the participants were asked at the end of the interviews how they were feeling as a check regarding their state, and all reported at the end of the interviews that the process had been overall, a positive experience.

The Participants

Eight participants were interviewed for the purposes of this study, seven women and one male. While this study had originally planned to only interview women, the male participant left a message saying he had a recording of his wife's experiences made prior to her death. While this recording was not able to be used, the male participant was interviewed in terms of his experiences, observations and insights into his recently deceased wife's illness. This participant however had kept copies of a large amount of paper information which he gave me access to. This information was such that, combined with his interview, the decision was made to present it as an individual case study in the Ninth chapter of this thesis, and was excluded from the body of the data. My own experiences as a participant-observer have also been included with those of the women participants which brings the participant total to nine.

DATA COLLECTION

Data was collected from September 2000 through to December 2000. The participants were interviewed by myself during that time, both in face to face contacts and over the telephone. Face to face interviews were audiotaped and transcribed. Written fieldnotes were taken at the time of the interview and were more fully written up within twenty-four hours of the interview. Telephone contacts were recorded as written notes.

The interviews were conducted as semi-structured in depth interviews. That is, while I followed a planned interview format (Included as Appendix Two), the

interview itself was not conducted in a 'question-answer' manner. I began with the first question on the interview format, then allowed the interview to progress as a conversation. Throughout the interview, I made a mental note of the questions that had been addressed within the conversation, and towards the completion of the interview itself, checked the interview question format as a prompt to include those areas that had not come up as part of the conversation. The narrative of the participants was therefore the primary source of data from which analysis occurred, and remains central to the methodological paradigms undertaken within this study.

This is not to imply however that the narratives of the participants was the **sole** source of data. A growing number of social researchers advocate the use of strategies of triangulation to interpretative research (Bell & Newby, 1976; Louis, 1982; Denzin, 1989) and this includes disability and feminist researchers (for example, Stanley & Wise, 1983; Harding, 1987; Boyles, 1994). Combining separate sets of data can allow a more complete, contextual representation of the research participant's experiences and, in doing so, contributes to construct validity.

In addition to the interviews conducted, I made observations of interactions with others (where these occurred) including interactions with family members, caregivers or home helpers, or where I was party to interruptions by telephone calls or visitors. I also wrote fieldnotes of the interview and the observed living situation of the participants. Prior to the interview being conducted, the participants had completed an information sheet which gave basic information about themselves, the physical impact of the disease upon them, and what permanent impairment they experienced.

Six of the participants gave me access to a variety of forms of written records. These included copies they held of their medical files, letters and documents from a variety of agencies and healthcare providers, and letters they had written in response. One participant had kept a diary of her experiences, and one gave me access to poetry she had written. Writers such as May (1993) and Sarantankos (1993) recommend the use of documentary information to supplement information obtained from research participants.

DATA ANALYSIS

Transcription and Accuracy

Tapes were transcribed verbatim by a typist employed through the Massey University Disabilities Co-ordinator. Once completed, copies of both the transcripts and the fieldnotes made were sent to the participants to check for accuracy and to correct if they wished to do so in order to confirm face validity (Boyles, 1994).

The process of sending information back to participants for checking and correcting is also important in terms of an emancipatory paradigm; in so doing, the importance of the information is validated. Additionally, being able to see and correct or elaborate on one's own narrative can allow a participant the opportunity to evaluate and validate their own described experiences, including recognising the ways in which they have responded to (including ways they have resisted) situations. This can encourage empowerment in that through the process of creating meaning during an interview, they confirm their own struggles and knowledge as being important and valid. It can also provide a record of the ways in which they have managed difficult or oppressive situations.

One participant was not sent a copy of the transcribed interview and fieldnotes at her request. Each participant was contacted a week after the receipt of their transcript, and any alterations or changes to be made were noted prior to data analysis commencing. Data analysis took the following forms throughout this study:

Content Analysis

Content analysis, as defined by Patton (1990:381) is “the process of identifying, coding and categorising the primary patterns in the data”. The narrative of each participant was thematically coded in terms of the relationship, positive and negative, between the data and the research questions. It was further coded in a similar fashion, in terms of the relationship to the theoretical constructs being examined, and unanticipated or emergent themes. Fieldnotes and records were similarly coded. In order to avoid unnecessarily skewing the data, where records confirmed or validated interview data, it was noted, but not recorded as an additional response. New information emerging from the data was coded as a separate response. Finally, negative coding (Tolich & Davidson, 1999) was undertaken in order to identify strengths and particularly weaknesses within the data collection process in order to inform future research design and identify limitations of this study.

Case Analysis

The coded transcripts, fieldnotes and written data collected were drawn together for each participant, and from all the information obtained, a topical case record was developed which summarised the emergent themes identified within the coded data. Finally, a cross-case analysis compared the similarities and differences between each participant’s data to bring together a summarised analysis that could be applied to the theories under examination.

Each summarised thematic analysis has subsequently been applied within the following chapters of this thesis.

CONCLUSION

This chapter set out to achieve a number of objectives - to specify how this study was designed and carried out and to identify and make explicit the methodological underpinnings that formed the foundations of this research design. I also endeavoured to present a record of the problems faced, and the process undertaken to create solutions when confronted with a disablist, patriarchal response to a genuine research inquiry.

What should be noted at this point however, is that this response was not, it appeared, an attitude mirrored by the regional Multiple Sclerosis Societies of the areas in which I conducted my research. A very positive message was left for me by the Field Officer of one region thanking me for including my advertisement for research participants in their local newspaper during MS Awareness week. Regretfully I was unable to respond to her call, but I found it interesting to discover that even though each regional society is not bound by the decisions of the Research and Advisory Committee of the National Multiple Sclerosis Society, the Committee does not inform the regional societies, and therefore its members of the decisions it makes **on their behalf**. I would therefore suggest that discourse is not only about what is communicated, but it is also about what is never exposed for the scrutiny and comments of disabled people.

The only preconceived political agenda belonged, I believe, to the National MS Society's Research and Advisory Committee. I doubt that the rigours of reflexive practice and the process of locating oneself has been undertaken within this forum, particularly given that at that meeting they decided to support

a quantitative research project being undertaken by a medical school researcher. I have read the questionnaire sent out by the school of medicine, and took Finkelstein's (1985) advice - that if it is not conducted by disabled people (or within partnerships between disabled and non-disabled people), for disabled people, in the interests of effecting change for disabled people, then don't participate. The information sheet attached to the questionnaire claimed to be interested in effecting change for disabled people - I wait in anticipation for the outcome.

The research design and methodology of this study forms the basis upon which the remainder of this thesis is developed. In order to be able to apply and discuss the data obtained to the theoretical constructs in question in a way that makes sense to the reader, it is essential to first gain an understanding of Multiple Sclerosis - the disease itself, and the participants' experiences of the disease. It is to Multiple Sclerosis that I now shall turn.

PART TWO:

OPPRESSION?

DATA RESULTS

AND

DISCUSSION

CHAPTER FOUR: WHAT IS MULTIPLE SCLEROSIS?

INTRODUCTION

The following chapter introduces the reader to the disease Multiple Sclerosis (MS). In order to create a clear understanding of the medical components of the disease process, a medical framework has been utilised which defines and classifies MS and discusses the aetiology and epidemiology of the disease. Clinical aspects of the disease are outlined, including symptoms experienced, comorbid features and finally, the process of diagnosis and its treatment or management (For those unfamiliar with the medical terminology used, please refer to the Glossary of terms attached as Appendix Four).

Following this, the reader is introduced to the research participants in this study, and their data is presented to provide an overview of the ways in which the disease impacts on them at a personal level. This information is deliberately presented using the medical framework above, to provide an illustration of the clinical aspects of the participants' experiences with Multiple Sclerosis. In doing so, the reader may begin to appreciate the medical framework that defines and articulates the disease; a framework which all people with Multiple Sclerosis find themselves encapsulated by prior to, and/or at the time of diagnosis. In order to be diagnosed with MS, one must enter this framework; in order to receive healthcare or welfare services once diagnosed, currently one must remain within that framework.

WHAT IS MULTIPLE SCLEROSIS?

History

Multiple Sclerosis was first identified as a distinct disease in 1868 by Jean-Martin Charcot [1825 - 93], a clinical professor of the nervous system; and the lesions formed by MS were illustrated by Jean Cruveilhier in his *Anatomie Pathologique du Corps Humain* [Pathological Anatomy of the Human

Body, 1829 - 42], relating the symptoms experienced by patients to 'grey degeneration' within the brain and spinal cord. Friedrich Theodor von Frerichs [1819 - 85] made an earlier extended clinical study in 1849 (Porter, 1997).

While numerous neurologists at this time were studying and describing the symptoms and/or the pathology of this neurological disease (and others), it was Charcot whose (1872) textbook based upon his *Lecons sur les Maladies du Systeme Nerveux Failtes a la Salpetriere* [Lectures on Nervous Diseases Delivered at Salpetriere] presented Multiple Sclerosis as a named disease described in terms of signs and symptoms in the 'classic patho-anatomical manner' (Porter, 1997:546).

Definition and Classification (*What is MS?*)

Definition

'Sclerosis', literally translated, means hardening or scarring, and refers to the scars (sometimes called plaques, or lesions) within the central nervous system (CNS) which are the end product of the disease process. Following an attack on myelin (the fatty protective covering of nerves), damage is caused to the myelin sheath. As with damage anywhere else in the body, as the area recovers, scar tissue is formed as an end product.

'Multiple' refers to the way in which these scars are scattered throughout the CNS - the brain and spinal cord (Perry, 1994). The scars of MS affect the transmission of nerve impulses from the brain and spinal cord causing the symptoms experienced and neurological signs of the disease. Symptoms generally correspond to the areas of the CNS which have been affected by the disease.

Classification

The *International Classification of Diseases (ICD)* categorises Multiple Sclerosis as a neurological disease, and identifies it as a demyelinating disorder due to the destruction of myelin that occurs. However, debate around MS has resulted in it being alternatively classified as an autoimmune disease (Vorhaus, 1999) or a vascular, genetic, endocrine or metabolic disorder (Graham, 1987). Multiple Sclerosis is often further classified according to the ways it presents in patients. The types of MS include:

- *Relapsing-Remitting Multiple Sclerosis*. In this type, people with MS experience unpredictable flare-ups of the disease (called relapses, attacks or exacerbations) during which new symptoms appear, or existing symptoms become significantly worse. These can last for differing periods of time (from days to months), and are followed by a full or partial recovery, known as remission. The disease may then be clinically inactive for weeks, months or years.
- *Benign Multiple Sclerosis*. Benign MS is usually diagnosed between ten and fifteen years after onset (MSSNZ, 1999) and is initially diagnosed as Relapsing-Remitting MS. However, after one or two exacerbations with complete recovery, this form of MS does not progress over time and there is no permanent disability.
- *Secondary-Progressive Multiple Sclerosis*. For many people with MS who have initially had Relapsing-Remitting Multiple Sclerosis, the disease pattern can change over time. The recovery from attacks becomes less complete, or progressive impairment begins to increase and there are fewer clear-cut attacks, although these can occur as well.
- *Primary-Progressive Multiple Sclerosis*. This form is characterised by a steady onset with slowly worsening symptoms and increasing impairment.

There is usually a lack of distinct exacerbations of the disease, although these may occur as well as the progressive impairment (MSSNZ, 1999 a).

Aetiology (What Causes MS?)

Over the past 130 years there have been numerous debates and masses of research conducted in an attempt to identify the cause(s) of Multiple Sclerosis. Most of the current research into the cause of MS is being carried out in the areas of genetics, cell biology, immunology and virology. Past studies have focused on the interaction between environmental and genetic factors (Matthews et. al., 1991) which examined the relationship between the geographical environment one is brought up in and the effects of migration from high to low areas of risk. The impact of trauma and stress is one area in which socio-environmental aspects of MS have been studied, and while such studies have suggested a link between high levels of stress and exacerbations of the disease, no conclusive results were obtained to suggest that stress or trauma can trigger or cause the disease (see for example, Van der Plate, 1984; McLellan et. al., 1989; Bauer & Hanefeld, 1993).

The two major current theories about the cause of MS relate to slow viral infection and autoimmune system response (Perry, 1994). In both approaches, a viral infection is thought to be responsible for MS in adulthood - either by a childhood viral infection remaining latent (or dormant) throughout childhood and early adulthood then becoming reactivated somehow; or by the body's autoimmune system mistakenly attacking its own tissue - in this case, myelin. Alternatively, it is suggested that the body's immune system may be triggered by a virus to attack both the virus and myelin.

Current research therefore tends to focus on finding the 'cause' (and with that, possibly the 'cure') of MS within the body rather than balancing this with

environmental mechanisms or processes outside the body. Perry (1994 : 6 - 7) debates the ethics of such an approach, claiming that scientists and media reports subsequently imply that they are on the verge of discovering the cause (and therefore the potential cure) of the disease which provides hope in the short term for people with MS, but can lead to despair in the long term; and Cornell (1992) argues that the time it will take to find a cure is a luxury that some people with MS do not have.

Epidemiology (*Who gets MS?*)

Multiple Sclerosis is one of the most commonly acquired neurological disorders in young adults. Incidence rates of MS are positively associated with gender, age, ethnicity and genetic and environmental factors such as geographical location and migration.

In terms of gender, women are affected more frequently than men (Matthews et. al., 1991; MSSNZ, 1995) with the imbalance world-wide ranging between 1.2 and 2.0 women for each man diagnosed. The risk of developing MS increases with age from mid adolescence, peaks in the early thirties, following which it declines with age (Perry, 1994). Therefore, diagnosis is rarely made before fifteen, and is unusual after the age of fifty (MSSNZ, 1995).

Multiple Sclerosis affects Caucasians more than any other ethnic group. It is rarely seen in Asians, Eskimos, Native Americans or Africans living in Africa - African - Americans however, develop MS more frequently than those living in Africa, although still less frequently than Caucasian Americans. In Aotearoa New Zealand, Maori and Pacific Island people are infrequently affected.

There appears to be a genetic susceptibility to developing Multiple Sclerosis, although it is not inherited. If a close member of the family has MS, then

chances of developing the disease increase. Approximately ten percent of people with MS also have a near relative with the disease. If a parent, sibling or fraternal twin has the disease, a person's chances increase from 25 - 75 per 100 000 to between 1 in 50 or 1 in 100. If an identical twin develops MS, then the risk of the other twin increases to 35% (MSSNZ) (1999 b). However, the fact that 65% of identical twins do not develop Multiple Sclerosis points to an as yet unidentified environmental factor also being involved in developing the disease.

Known environmental contributors include geographical latitude - risk increases with distance from the equator. People located in the cooler climates of northern and central Europe, Canada and Southern Australia and Aotearoa New Zealand are at higher risk than those living closer to the equator. Studies indicate that migration from high to low risk areas (Matthews et. al., 1991; Dean & Elian, 1997) in early life reduces the risk of later developing the disease. However, migration to a low risk area after the age of fifteen means the risk remains as high for an individual as it would have been had they not migrated.

CLINICAL ASPECTS OF MULTIPLE SCLEROSIS

Symptomology (*How does MS affect People?*)

The symptoms of Multiple Sclerosis are highly individualised and depend on which parts of the central nervous system have been demyelinated and how much nerve tissue has been destroyed. Every person with MS therefore has a set of symptoms unique to themselves, although any combination of the following may occur: altered sensation, balance and co-ordination problems, bladder and bowel problems, weakness, paralysis, spasms, abnormal speech. Vision can be affected either with blurred or double vision, or vision loss. Debilitating fatigue is frequently reported, and pain may be experienced as a

consequence of spasticity, sensation changes or as an individual symptom. Less frequently, epileptic seizures or headaches may be present.

Psychological and psychiatric symptoms of Multiple Sclerosis have been debated at length within professional journals (for example, Peyser et. al., 1980; Schiffer et. al., 1983; Kellner et. al., 1984; Mclvor et. al., 1984; Heaton et. al., 1985; Halligan et. al., 1988; Averbuch-Heller et. al., 1992; Evers & Karnilowicz, 1996 or Barnwell & Kavanagh, 1997), particularly in terms of cognitive dysfunction and psychiatric illness and the disease.

It was previously believed that cognitive dysfunction was rare and if seen, was considered part of the end stages of MS. This attitude has begun to change only recently in recognition that cognitive problems do occur for a number of people with MS. (Heaton, et. al., 1985; Halligan et. al., 1988; Hight, 1999). Furthermore, while Multiple Sclerosis is not considered to be a psychiatric disorder, there does appear to be either an increased risk of some psychiatric problems, particularly mood disorders for example, depression or bipolar disorder (Kellner et. al., 1984; Averbuch-Heller et. al., 1992; Wolf, 1996), or these may be MS symptoms in their own right.

Symptoms tend to fluctuate within individuals. They can disappear, reappear or change on a daily basis. No one person with Multiple Sclerosis has all the possible symptoms, and for each person with MS, the course of their disease is unpredictable and individual, making prognosis difficult.

Diagnosis (*How can you know you have MS?*)

Multiple Sclerosis is notoriously difficult to diagnose due to the variable and transient nature of symptoms, and the absence of a single diagnostic test. A combination of several tests and examinations over time are often required

before a diagnosis can be made. These will or may include medical and neurological examinations, blood tests, a lumbar puncture, evoked-potential tests and/or brain and spinal cord scans. As many of the symptoms of Multiple Sclerosis can also be symptoms of other diseases, great care must be taken to avoid misdiagnosis. The advent of computerised axial tomography (CAT Scan) and magnetic resonance imaging (MRI) has brought some advances in the early detection of MS (Webb, 1992), but even with these advances, it requires a combination of test results to be able to confidently diagnose the disease.

For some people with MS, none of the tests are conclusive, and a diagnosis may take years as specialists observe the symptoms for a clinical picture of exacerbation and remission. The time it takes to diagnose Multiple Sclerosis, the way in which the diagnosis is (or is not) conveyed to people with MS and the information they are given about the disease at the time of diagnosis can impact negatively in terms of patient dissatisfaction with medical practitioners (Wright, 1992; British Society of Rehabilitation Medicine, 1993; Perry, 1994).

Management of Multiple Sclerosis (*What can be done for MS?*)

Multiple Sclerosis is a disease which has no cure, and the very nature of the disease makes it difficult to assess the efficacy of many treatments - what works well for one person may fail miserably for another. Furthermore, due to the changing nature of the disease, what works well for one person one week, may fail the next. Medical treatment of Multiple Sclerosis (until recently) fell into three main categories; treatment of symptoms, treatment of acute exacerbations and prevention of secondary problems.

The treatment of symptoms such as spasticity, bladder or bowel problems, pain and depression draws on a variety and combination of medications, physical and occupational therapies, bladder and bowel management strategies,

orthotic or mobility aids and counselling to manage symptoms as effectively as possible.

Acute exacerbations of the disease may be treated with high doses of steroid hormones such as Adrenocorticotrophic Hormone (ACTH) or synthetically produced versions of these (for example, Prednisone, Prednisolone, Methylprednisolone, Betamethasone, Dexamethasone) which act by reducing the inflammation of an exacerbation as well as suppressing the overactive immune response involved in an acute flare up of the disease.

Secondary symptoms of Multiple Sclerosis include problems like contractures and injuries of joints and limbs, pressure sores, bladder infections which over time can lead to kidney problems, constipation, obesity and chest infections or pneumonia. Most of these problems can be avoided with careful ongoing management and care from a variety of personnel, and particularly through daily management by the person with MS and /or their caregivers.

Altering the course of the disease

Within the past ten years, three major treatment options have been made available to people with Multiple Sclerosis which have been evidenced through clinical trials to alter the course of the disease itself. Known collectively as the 'A B C's' of MS treatment, these options comprise:

Avonex (Interferon beta 1a)

Betaseron or Betaferon (Interferon beta 1b) and

Copaxone (Glatiramer acetate - formerly Copolymer 1)

These act in different ways to reduce the number of relapses experienced by people with MS as well as to reduce the progression of the disease itself (van den Noort in Hinson-Smith, 1998). While the complexities of these treatment

options are beyond the scope of this chapter, the Interferons are defined as “a group of immune system proteins, produced and released by cells infected by a virus, which inhibit viral multiplication and modify the body’s immune response” (Kalb, 1996:16). Copaxone is a synthetic compound, developed in 1967 at the Weizman Institute of Science in Israel. Resembling a component of myelin, it is believed to act as a ‘decoy’ (Stoneham, 1997) within the body, tricking the body into attacking the drug molecules rather than myelin.

It is only since the end of 1999 that funding was approved for the treatment of 180 people with Relapsing-Remitting MS in this country with Interferon beta (Avonex or Betaseron) and Copaxone is currently being considered by the Ministry of Health for use in this country and is to date unavailable. Aotearoa New Zealand was one of the last Western countries to agree to fund these treatments, and the capped numbers of funded individuals means that treatment options currently remain extremely limited for people with MS in this country.

Alternative treatments

A large number of alternative treatments and therapies have been trailed over the years, from the use of hyperbaric oxygen chambers to bee venom therapy; combinations of medications, for example, the Cari Loder treatment; diet and the use of supplements (Graham, 1987), or combinations of any of the above. Many of these have been clinically tested and found to have little direct impact on the clinical course of the disease. (Sibley, 1996). Regardless of clinical testing, a number of people with Multiple Sclerosis make use of a combination of medications, natural treatments (particularly evening primrose oil and cranberry juice) and diet to manage living with the disease.

This then, is a brief overview of the disease, Multiple Sclerosis. Perhaps one of the most appropriate terms to use for the disease is 'defiant'. MS defies early detection and immediate diagnosis, prediction, prevention or prognosis. It defies medicine and science with its intractability, unpredictability and resistance to treatment. It defiantly marches on, from generation to generation, for the past 130 years; offering small clues as to its cause, leaving no doubts about its effect. This defiant disease is lived with daily by 2,394 identified people with MS in this country (Highet, 1999), 1,864 of whom are women. Eight of those women now present **their** clinical picture of Multiple Sclerosis.

THE PARTICIPANTS: GENERAL DATA

Age: The eight women were aged between 35 and 68 years , with a mean age of 46.6 years.

Family Situation: One participant described herself as single, with one child (deceased) and living with a parent. Two of the women were separated, one raising a child alone, and one who had three adult children, none of whom were living at home. One participant was divorced, currently in a long term relationship, with one child from her previous marriage. Three of the women were married, each with two adult children not living at home. One participant was widowed with three adult children, none of whom lived at home.

Living Situation: Two of the participants lived in rented accommodation, the remaining five were in their own freehold (two) or mortgaged (three) homes.

Work/Study Situation: One participant worked full time. She was also undertaking a full time course of study. One participant was unemployed (not in receipt of Income Support) and was studying. Three participants worked part time, one of whom was in receipt of the community wage and working

according to the requirements of this welfare assistance. Two participants were in receipt of the Invalid's Benefit and one was retired on National Superannuation.

WHAT IS THE EXPERIENCE OF MULTIPLE SCLEROSIS?

The wonder of this amazing disease? Yes, oh Yes! I've always said, "At least it's not boring. If you have to have something, MS does lend excitement!" Mary J. Stewart, in Wolf et. al. 1993.

Definition and Classification of Multiple Sclerosis

All of the participants interviewed had a confirmed diagnosis of Multiple Sclerosis (as previously defined) for at least three years. Of the group, none had a diagnosis of Benign MS; six (aged between 35 and 68 years) had Relapsing - Remitting MS and two had the Secondary - Progressive form of the disease.

Aetiology of Multiple Sclerosis

Several of the participants had their own hypotheses around what factors had triggered or caused their Multiple Sclerosis. In the two years prior to diagnosis of MS, all of the participants had experienced significant life events. Four of the participants had had surgery, one of whom developed her symptoms of MS within two weeks of her surgery, and one of whom had almost died.

Three of the participants had given birth (a risk factor for an exacerbation of the disease), one of whom developed MS symptoms within six weeks of the birth of her child, and one of whom felt she had never 'picked up' following a traumatic caesarean two years prior to her diagnosis being made. This participant considered that the epidural injection she received at the time contributed in some way to the problems she experienced, and another participant also experienced initial symptoms within a week of having an epidural injection.

At the time of diagnosis, one of the participants already had an autoimmune disease, and another developed a second autoimmune disease after diagnosis. Both of these participants supported the current thinking around autoimmune problems. Two of the participants felt that immunisations had contributed to a) a worsening of symptoms, and b) an exacerbation following the injection, although neither believed that the immunisations had caused their MS.

Two participants had experienced 'other' stressful events in their lives (family and work problems) which they felt contributed to the appearance of MS symptoms. While none of these factors has been identified as a stand-alone cause of Multiple Sclerosis to date, all of them can constitute an insult to the body's immune system, which responds to any trauma in a similar way.

Given the current thinking around autoimmune response or an over response of the body to trauma, what is interesting to note is that three of the participants experienced multiple insults (three or more) to their immune systems in the two years prior to their symptoms becoming apparent; and these three experienced rapid exacerbation rates or severe permanent symptoms following them. As Natasha describes:

*I'd had spinal surgery in October, went overseas in February and caught a foul virus from which I didn't really recover. I had an epidural injection in April, followed two weeks later by a tetanus injection and polio sip. I don't know that any of these **caused** my MS, but I think that together, one on top of the other, my immune system just fell over.*

Epidemiology

All of the research participants except one were Caucasian New Zealanders. As participant-observer, my heritage includes links to Ngati Porou and Ngati

Kahungunu Iwi, which means I am one of the few Maori or Pacific Island people with Multiple Sclerosis in this country.

The age of the participants at diagnosis varied; two were in their early to mid twenties when diagnosed, while one was diagnosed at the age of 57 years. The remainder were diagnosed between the ages of 32 and 42, with a mean age of 36 years. In terms of genetic susceptibility, three of the participants had near relatives who also had Multiple Sclerosis, one of whom has a sibling with the disease, one a first cousin and one a nephew.

CLINICAL ASPECTS OF THE DISEASE

Symptomology

At the time of consenting to participating in this study, the participants were asked to complete a brief personal information sheet which outlined which symptoms they had experienced in the past, as well as those they considered to be a permanent feature of their disease. The following table records their responses to these questions.

Figure 4.1: Multiple Sclerosis Symptoms (Past and Permanent) experienced by Participants.

Symptoms	Past Symptoms	Permanent Symptoms
Bladder / Bowel	6	3
Cognitive / Memory	2	2
Vision	6	2
Balance	8	3
Movement / Mobility	8	7
Sensation	7	4
Speech	3	0
Fatigue	7	3
Other - Pain / Neuralgia	2	2
Other - Depression	1	1

The question of permanency of symptoms is a difficult one to respond to, given the nature of the disease, with symptoms that appear and disappear. Definitions of the term 'permanent' vary across and between medical disciplines, as well as between service agencies in health and welfare. The concept of 'permanent' symptoms also varies between people with MS. The responses above therefore reflect what the **participants** consider to be permanent features of their disease.

Diagnosis

As discussed earlier in this chapter, the diagnosis of Multiple Sclerosis is a difficult one to make. For two of the participants in this study however, the process of diagnosis was rapid; Rebecca was seen, faced a barrage of tests, including an MRI scan and within three weeks was told what the cause of her paralysis was. Similarly Marie, who has a sibling with MS, was immediately MRI scanned and knew what the outcome of this was within a brief period of time.

Kate had tended to blame her MS symptoms on her other autoimmune disease (already diagnosed) which had many similar symptoms and for many months, so did her specialist. Once she became aware there were symptoms which did not relate to this disease, she alerted her rheumatologist, and Multiple Sclerosis was tested for and confirmed although the process took a lengthy period of time due to waiting lists within the public health system.

Josetta had presented to hospital some nine years prior to diagnosis, and was diagnosed with 'hysterical paralysis' (although not informed of this diagnosis until she later obtained her medical records). On presenting again four years later with new symptoms, she was not tested for MS. Five years after this, she developed optic neuritis, and Multiple Sclerosis was positively confirmed, but the neurologist did not tell her it was this - and wrote to her general practitioner

advising the same. [confirmed by her medical records]. In order to 'get' her diagnosis confirmed, she had to request a second opinion.

Daphne faced similar problems. When she first presented to her General Practitioner with symptoms of MS, he refused to refer her to a specialist. She had to dare him to have her forcibly removed from his clinic without a referral before he would write one. Then, after having a lumbar puncture and brain scan performed, she was told by the neurologist she did not have Multiple Sclerosis. A year later, still experiencing symptoms, she returned to her General Practitioner and challenged the decision. He told her that the neurologist had changed the diagnosis three weeks after she'd seen him and she did in fact have MS.

Natasha, while being clearly told she had a neurological problem, was one for whom the initial tests and scans revealed no evidence of Multiple Sclerosis. The diagnosis therefore, had to be made over time as the disease provided a clearer clinical picture of exacerbations and remissions, and other possibilities were eliminated. She was however told from the outset that MS was one of the possible options for diagnosis. Debbie also experienced a lengthy waiting period to have a diagnosis of 'probable MS' confirmed as Multiple Sclerosis.

Maxine initially was not told she had 'probable' MS, but her husband was warned two years prior to the diagnosis being confirmed that this was a possibility. She was informed of the diagnosis as soon as it was made, but later did not know she had secondary-progressive MS until her application for treatment with Interferon beta was turned down this year on this ground.

Management of Multiple Sclerosis

All of the participants utilise a variety of treatments and strategies to manage their disease. A number of them take medication to manage symptoms of spasticity, bladder dysfunction, depression and pain. Some augmented these with diet, dietary supplements and alternative remedies. Several of the women require the use of incontinence products to deal with bladder difficulties. Four of the women used orthotic aids (splints) and crutches or canes to aid mobility, while two used wheelchairs regularly, one of whom uses a wheelchair most of the day.

The majority of the women had hand rails at entranceways and/or in bathrooms/toilets to assist with climbing steps or transferring to the bath or toilet; two participants had completely modified bath and/or toilet areas. Three participants had home help or personal care attendants to help them with daily showering, toileting, exercises or assistance with household chores. All of the participants had in many ways altered their lifestyles, leisure pursuits, routines or roles within and outside their homes to manage the impact of living with the disease.

In terms of altering the course of the disease, two of the women in this study were receiving treatment with Interferon beta. One was in the process of applying for treatment, and two had made enquiries, but were ineligible due to having a diagnosis of secondary - progressive MS. The remaining two women did not meet the criteria for treatment, one of whom however, has no interest in pursuing this option.

CONCLUSION

This then is an overview of the clinical picture of the participants in this study. All of the participants have permanent impairments ranging from an inability to

run to requiring daily assistance for showering, preparing meals and mobility. Half of these participants appear 'normal' in the community at large, yet of this group, two struggle daily with severe pain, one of whom also experiences severe depression and cognitive impairment.

The clinical picture of the disease is therefore not enough to truly understand what life is like with Multiple Sclerosis. In order to gain a better appreciation of the lives of these women, one must look to the meanings they attribute to their experiences, to their disease, the people who treat the disease, and to the ways in which society responds to their needs. The remainder of the data which is presented over the next four chapters further explores these issues.

CHAPTER FIVE: FOUCAULT, MEDICALISATION AND MULTIPLE SCLEROSIS

INTRODUCTION

Chapter Four discussed the clinical aspects of Multiple Sclerosis, as well as the lived experiences of this disease for the participants of this research. A medical framework was deliberately utilised to provide a picture of the structure that people with Multiple Sclerosis are most frequently placed within. This chapter examines this framework in terms of Michel Foucault's analysis of the technologies of power, knowledge and discourse. The medicalisation of disability is revisited, and some of the tensions of applying this to a disease such as Multiple Sclerosis are discussed.

The experiences of the women involved in this study are then presented in terms of their relationship to the theoretical discussions above, followed by a discussion of these results, including discussion on some of the unanticipated issues raised by the data in terms of a 'remedicalisation' of disability for some of the participants as they have pursued or obtained treatment for their disease.

MICHEL FOUCAULT: A MODEST, SUSPICIOUS POWER

In *Discipline and Punish* (1977), Foucault describes and analyses how power operates at all levels in society and is maintained through what he calls 'technologies of power'. Such technologies of power are diverse and insidious, changing according to the groups, places and points in time in which they are operating; and produce disciplined individuals as a consequence.

Foucault asserts that 'discipline is what 'makes' individuals' (1977:170); a power's technique which perceives the individual as simultaneously its object of knowledge and power and its instrument for creating the object - its subject.

The success of discipline is remarkably simple; Foucault suggests it is the use of three key tools by which power maintains its 'omnipotence' (1977:170). These tools are:

Hierarchical Observation

Hierarchical observation is a tool of power described by Foucault as a 'mechanism that coerces as a means of observation' (1977:170). Within his archaeology of the clinic (*The Birth of the Clinic*, 1973), Foucault used the French term 'regard', which has been translated as the 'gaze' to best reflect the intent of this discourse.

Hierarchies of power occur because observers (those having power at a given time) structure systems in such a way as to obtain the co-operation of members of the observed population who in turn observe and report back on their peers. For example, within the education system, teachers (the observers) gleaned school monitors and tutors from the ranks of their most adept students. These groups reported back on their peers to the teacher. This maintained discipline in that those pupils whose bad behaviour was not 'seen' by the teacher were still 'observed' to have transgressed through the monitoring of their peers, a practice still seen today in school prefect systems.

Similar hierarchies existed within prison, military and hospital systems (and still do) and functioned with remarkable precision, allowing 'discipline and power to be absolutely indiscreet as it is always everywhere... and absolutely 'discreet' for it functions permanently and largely in silence' (Foucault, 1977:177).

Normalising Judgement

Foucault describes in detail a combination of punishments for 'bad' behaviour and the development of reward systems for 'good' as effective tools for

discipline at the individual level as well as for the masses. His descriptions of the subtleties of reward systems such as grades and ranks, the use of repetitive punishments as well as the ability to move from one rank to another according to conduct makes this tool a double-edged sword - one that can punish **and** reward in one stroke.

Under such circumstances, individuals become aware that it serves their interests to **conform** to achieve a higher rank or reward. As they strive to achieve such a goal, they collude with the hierarchical observation already in place by observing themselves and others to ensure their own rewards.

In punishing and in rewarding, Foucault identifies five operations which create and sustain the 'art' (1977:182) of discipline. These are:

- Comparison, differentiation, adherence to an identified rule or rules.
- Individuals, differentiated from one another, are measured in quantitative terms.
- Hierarchies are therefore developed.
- Through such 'value giving' (1977:183) terms, conformity is developed, which -
- Defines limits and boundaries by which each difference is compared within the limits of every other difference - it defines what is abnormal, and therefore it **normalises**.

The Examination

The examination combines the first two tools to essentially consolidate the observer and the observed in a structured and formal way. The examination provided evidence of ability and enabled inclusion; it also allowed by comparison for the exclusion of those who did not fit the 'norm' and continues

to do so today. It is the examination, claims Foucault which 'maintains the individual in his [sic] subjection' (1977:187). The individual who strives to perform in a disciplined way (to fit the norms of society) that he or she may be rewarded (by somehow, invisibly or overtly being observed) becomes subjected to this examination; becomes also the object of the examination by which they are compared. And in so doing, the individual internalises the discourses of observation and normalisation to become a disciplined subject within a power structure.

The power of the 'gaze' thus ceases to be a tangible, identifiable 'person', it becomes instead an invisible, untouchable construction by which an individual is as much a subject to as an object of that power. Such power operates at all levels; it is 'multidirectional, it comes from below, sideways and above' (Sullivan, 1996:25). In utilising the technologies discussed above, power produces 'reality' through 'rituals of truth' (Foucault, 1977:194) through discourse, and survives as 'a modest and suspicious power, which functions as a calculated, but permanent economy' (Ibid:170).

Discipline: Impaired people as subject / object of knowledge and power

The implications of such an analysis for impaired people are both complex and compelling. Foucault's analysis of power within the education, hospital, asylum and military systems provides a clear and concerning picture for those who do not, or who **cannot** fit within definitions of the 'norm'. Impaired people are all too often under the 'gaze' of the medical and welfare systems, and this is no exception for those diagnosed with Multiple Sclerosis.

Given that MS is notoriously difficult to diagnose and that people presenting with initial symptoms may not fit into a neatly constructed category or norm, they may undergo numerous medical tests or examinations to eliminate the

many other diagnoses that **could** be made of them. This process is essential and appropriate at this stage, as a misdiagnosis (and possibly inappropriate treatment) could have devastating consequences for a person with MS.

During this time, which may be as brief as a few days or as lengthy as several years, a discourse of medical and comparative terms develops which ranks and compares signs, symptoms and test results to reach a point of adequate knowledge to make a diagnosis. Such a discourse focuses on the pathology of the disease and begins the process of measuring an individual's **difference** to the 'norm' of healthy society.

From the point of diagnosis however, this process does not end; in fact the opposite tends to occur. The diagnosed individual is often further examined and ranked according to not only how they compare to the 'norm', but also to **others of their kind**. In order to access treatment, care or assistance, they become a 'case' (Foucault, 1977:91) or object for a branch (or several branches) of knowledge; described, differentiated and defined as 'abnormal' within able-bodied society.

Nowhere is this process more obvious at the current time than within the criteria set by Pharmac to obtain treatment with Interferon Beta. Due to government economic restrictions on access to this treatment, rigid entry and exit criteria have been set which people with MS are required to conform to for treatment. One must be **different enough** (in terms of their disease process and level of impairment) from others with Multiple Sclerosis to be able to apply for access to Interferon - but not **too different**; that is, neither too high nor too low on disability scales or have a diagnosis of primary or secondary - progressive MS. The foundations of these criteria are not laid down on the basis of scientific research, but have been set simply due to economic

restrictions, as current research indicates that not only is it important to begin treatment **before** significant impairment occurs, but also that Interferon Beta has indications for use for patients 'at risk' of developing MS (NMSS (USA) 2000; European Neurological Society, 2000); both primary-progressive (European Committee for Treatment & Research in MS) and secondary-progressive (NMSS (USA), 1998) forms of MS.

The assessment process to determine this difference requires further examination, ranking - and with that, value-giving (too high on the disability scale and a person is considered no longer 'worth' investing a costly treatment on; too low and we may become indifferent and 'waste' the treatment or alternatively, any improvement could not be further measured).

Such examinations of course are carried out by medical hierarchies who rank us according to our difference, and, based on economic criteria, decide whether or not we are 'eligible' for treatment. That is, in their inalienable right to examine, and treat (Zola, 1977), power resides within the medical profession who in this country, act as 'observers' for Pharmac. To be treated we remain subject to the knowledge and power of medicine; to remain on treatment we must undergo further processes of examination and ranking - to refuse to submit means the treatment is taken away as a 'punishment' - we therefore become disciplined subjects to medical discourse.

However, the technologies of power do not only apply to medicine. Foucault's analyses of other social structures and systems of the time apply well to these areas today. The welfare system of this country uses similar processes of hierarchical observation, normalising judgement and the examination to discipline subjects - and in the cases of people with diseases such as Multiple

Sclerosis, undertake such technologies by utilising medical discourse to determine eligibility for welfare assistance.

Welfare recipients and non - beneficiaries alike are encouraged to observe and report on those who may be 'cheating' the system which has ramifications for people whose symptoms come and go or whose symptoms may be invisible to others. A 'good MS day' may mean someone is seen working in their garden, and is 'reported' as being able to work. Their benefit is then cut off (usually without discussion first) and they must submit further to the gaze to have it reinstated. Finally, in order to maintain themselves on welfare assistance, recipients are also required to undergo frequent re-examinations to ensure they have not 'improved' enough to no longer warrant the benefit they are receiving.

For those who are working, the technologies of power may be used by some employers to monitor a person's performance or sick leave, to measure productivity and compare their output to their 'normal' colleagues. If the underpinning discourse of society perceives impairment as a negative construct, then such technologies of power serve to compare impairment and difference in a negative way. Such technologies, and their underpinning discourses do not only as Sullivan (1996) asserts, come from below, sideways and above: they also, given time, can emanate from within.

The internalised discourse of the disciplined individual

In teasing out the means by which technologies of power structured and maintained discipline, Foucault displays a fascination for the ways in which such technologies become internalised to the extent that an individual becomes self disciplined. Obviously under certain circumstances such a state is considered desirable within society - a complete lack of discipline results in anarchy or chaos.

When applied however to discourses of oppression, the internalised discourse of disciplined subjects becomes problematic. For example, a disabled individual who accepts unquestioningly that because they belong to a minority group they are an inferior subject, will behave in such a manner. In their discourse about themselves and in their behaviour they will expose the internalised belief that they **are** inferior.

This may occur in a number of ways - by attempting to strive towards a 'norm' they may not be able to achieve, or where invisible impairment occurs, by hiding their impairment to conform in a surreptitious way. If impairment cannot be hidden, attempts may be made to minimise its visual impact, for example a person may refuse to use a walking stick or wheelchair which, while it could make life physically easier, further advertises their 'abnormality' within able-bodied society.

Resistance: An alternative discourse

Gramsci (1971) asserts that discourse only exists with consent, and Foucault (1976) suggests that within power relations there is always the means for resistance. To resist, not only must consent be withdrawn, but a new discourse must be constructed. While the following two Chapters explore two such alternative discourses, resistance can occur in a number of ways - from resisting the internalised discourse of the disciplined individual, to having access to mentors, individuals or an alternative knowledge base that challenges or disputes the discourses and knowledge bases currently supported. The knowledge bases that support structures such as welfare assistance and access to treatment options are currently based upon the medicalisation of disability. But in examining such constructs in terms of a

disease like Multiple Sclerosis, a number of issues arise which must be addressed.

THE MEDICALISATION OF DISABILITY AND MULTIPLE SCLEROSIS

As discussed in Chapter Two, the medicalisation of disability locates the problem of disability within individuals, ensnaring them within an 'illness' model rather than perceiving disability as a political problem. Also discussed earlier was the debate that at times the use of 'labels' can validate women's experiences (Lonsdale, 1990) and that this was of significance as the diagnosis of Multiple Sclerosis at times provided relief from other labels. However, two further issues need to be raised at this point, one of which has been alluded to in the Literature Review and one which emerged over the course of this study.

Demedicalisation of a disease?

Firstly, there is the issue that Multiple Sclerosis **is** a disease process which at times requires significant medical input. While Michel Foucault was clear that he did not write

in favour of one kind of medicine as against another kind of medicine, or against medicine and in favour of an absence of medicine... (1973:xix),

many of the socio-political analyses of disability appear at first glance to be anti-medicine.

What must be noted at this point is that while the concept definitions of impairment and disability at the beginning of this thesis remain within the analysis of the data to be presented, recognition must also be made of the tension that exists in taking a 'pure' medical model **or** a 'pure' social model approach when examining an active, changing disease process. There are

times when Multiple Sclerosis demands medicalised intervention; on other occasions it is quite appropriate to apply a social model approach to discourses and social processes. I will suggest therefore that a key issue for people with MS perhaps, lies in maintaining the tension between the two perspectives in order to access the best that both models have to offer.

Remedicalisation of disability?

As the data analysis of this study progressed, an unanticipated issue began to emerge which raises the concern that, in the case of treatment with disease altering Interferon Beta, and also regarding other non-subsidised treatment options; a 'remedicalisation' of disability is occurring. That is, people with Multiple Sclerosis who have, to a large degree, exited the medical system are now required to re-enter it to obtain access to treatment. This issue will be discussed further later in this chapter.

FOUCAULT, MEDICALISATION AND THE EXPERIENCE OF MULTIPLE SCLEROSIS.

Data Results

The data analysis for this section identified the experiences (positive and negative) of the medicalisation of disability as well as applying the theoretical constructs of Foucault's technologies of power, subject/object position and internalised discourse to the coded data of the participants. In order to tease out the complexities of Foucault's analysis of the technologies of power, each of the 'tools of discipline' he describes were coded separately, as were references to subject/object positions and internalised discourse, which produced the following results:

Figure 5.1: Participant references to Negative Experiences of Power, Subject/Object Position and Internalised Discourse.

Name	Normalising Judgement	Hierarchical Observation	Examination	Subject Position	Internalised Discourse	Total
Daphne	1	2	2	5	2	12
Debbie	9	3	1	5	6	24
Josetta	6	8	6	10	12	42
Kate	3	12	3	15	2	35
Marie	1	5	4	4	11	25
Maxine	2	3	1	6	3	15
Natasha	4	3	4	7	1	19
Rebecca	2	1	1	2	0	6
Total	28	37	22	54	37	178

Also coded were references to resistance, strategies or access to alternative discourses to the experiences recorded above, which appeared to provide a protective counterbalance at time to these technologies. Additionally recorded within the following results were experiences where hierarchical observation or the examination were viewed by participants as positive:

Figure 5.2: Participant references to Positive Experiences of or Resistance to Power, Subject/Object Position and Internalised Discourse.

Name	Normalising Judgement	Hierarchical Observation	Examination	Subject Position	Internalised Discourse	Total
Daphne	2	3	2	3	0	10
Debbie	2	0	0	9	3	14
Josetta	0	1	0	6	9	16
Kate	2	7	1	7	14	31
Marie	0	1	1	3	3	8
Maxine	2	2	1	5	3	13
Natasha	2	1	0	2	5	10
Rebecca	2	1	2	5	9	19
Total	12	16	7	40	46	121

When examining the total recorded responses of the women in this study in terms of a Foucauldian perspective; their experiences of Foucault's technologies of power as negative outweighed their positive experiences or

strategies by a ratio of 1.47 to 1. Their positive and negative experiences of medicalisation occurred at a similar ratio of 1.5 negative to 1 positive. However, the experiences of these concepts were diverse among the eight women who participated in this study which are discussed below.

DISCUSSION

Hierarchical Observation

The participants all revealed experiences of hierarchical observation and an awareness at times of hierarchies of power within those experiences. Not all of these experiences were perceived by the participants as negative, although negative references outweighed positive experiences by 2.3 to 1. Reported experiences centred primarily around the medical profession, the welfare system and work.

In terms of experiences of hierarchical observation within the medical arena, most of the participants (six) reported negative experiences at or around the time of diagnosis, as they entered a process of moving through or 'up' a hierarchy of clinicians to obtain a diagnosis. For four of the participants these difficulties were made more difficult by occurring over lengthy periods of time, and these four continued to have problematic experiences post diagnosis.

Natasha, while finding the pre-diagnosis stage difficult to deal with, developed a collaborative working relationship with the medical team she was involved with, although:

This is not to say I didn't resent at times the intrusion into my life and home of multiple professionals...

For Rebecca, the experience of the hierarchy of the clinic (Foucault, 1973) was a positive one. She had been diagnosed rapidly and preferred being treated as

an individual rather than being compared to others. Marie also found the approach of the 'team' useful:

I really liked the team approach he was offering me... it was supportive at the time...

Marie had also been rapidly diagnosed, and what is interesting to note is that these three women all experienced a **team** of professionals rather than a hierarchy of individuals at the time they were diagnosed. Others such as Kate and Josetta found the hierarchy of the clinic difficult, both having been seen by a multitude of clinicians who did not communicate adequately with them or with each other. Kate in particular found the impact of the 'clinical gaze' at times difficult. For example, on visiting her General Practitioner, she described:

...and then he'd say, 'Walk in front of me'... I found that embarrassing in front of a waiting room full of people - perhaps he wanted to see if I could walk.

For Daphne however, the use of the 'clinical gaze' of a locum doctor became a life-changing event. Following a week in which she experienced multiple traumatic events, she presented to a locum General Practitioner who:

*...without me even telling him anything about myself, a man who had never met me in his life before, **looked at me** and said, 'Are you all right?' in such a way that I told him about myself. He hadn't even physically examined me - there must have been something on my face - and he sent me to [hospital].*

While there, Daphne was presented with an opportunity that became her future employment.

Three of the participants described experiences of hierarchical observation within Work and Income New Zealand (WINZ), where, in order to receive

income support they are required to submit themselves regularly to the scrutiny of that department. Natasha experienced an extreme form of the 'gaze' within her former workplace where she was constantly monitored as to her sick leave, working hours and outputs, while Debbie was beginning to experience being observed within her workplace as her condition changed.

Normalising Judgement

All of the participants also made reference to experiences of normalising judgement, ranging from their own internalised discourse around 'getting back to normal' (three participants), to people's responses to the discovery that a participant has MS or certain 'hidden' symptoms of MS such as bladder problems (seven participants). For one participant this included other's expectations that with treatment with Interferon Beta she should return to 'normal', defined by them as being able to walk again - and coming under considerable pressure to do so.

The experience of multiple normalising judgements in the form of multiple assessments impacted on two participants in particular, with Josetta reporting the highest number of negative responses [which were confirmed in part by the medical records she held] where she was frequently ranked and compared in order to receive what was often very limited assistance. Debbie also made numerous references to normalising discourse, many of which centred around a combination of subtle behaviours within her workplace.

All but two of the participants also reported positive experiences opposite to normalising judgement, or their own resistance or strategies used to counteract their experiences. Natasha, who had faced significant issues at one workplace, encountered an opposite response at a new worksite, in which she was

encouraged to assess the worksite to meet her needs rather than be expected to fit within a normalised site.

Daphne and Kate expressed what perhaps could be termed a 'renormalisation' as they aged - their peers, whom they had once been 'different' to, were now also slowing with age and as a result, were becoming more similar than different, which was viewed positively by both women.

Rebecca credits her own personality as providing her with the means by which to develop strategies of resistance to the few negative experiences she has faced:

...I've always had a very forthright, dominant personality, so if people don't like me, I don't care, you know; it's not an issue. Neither is it an issue that I have MS...

She also recognises that she has faced very few negative responses and thinks this has helped her develop her attitude. Marie uses the strategy of not telling people she has Multiple Sclerosis which acts as a preventative to being judged in this manner, while Maxine has an alternative approach of turning normalising judgement back on those who mete it out, as her response to a friend's comments about her wearing a 'plastic leg' (ankle-foot orthosis) illustrates:

*'You mean you **don't** have a plastic leg? Oh my gosh, I am so sorry for you, do you know it's the latest in fashion statements, you will all be wearing them next week', I said. They just sat aghast and so there was nothing more to be said, I just hopped off to the next conversation!*

The Examination

As discussed previously, Multiple Sclerosis is an unpredictable disease process, so not surprisingly all of the participants have undergone examinations and assessments for diagnosis and assistance for their physical or economic needs. Many of these examinations were negative experiences (a total of twenty-two references) while for half the participants there were occasional positive experiences as well (a total of seven references). Negative experiences centred around two key areas; the medical system and Work and Income New Zealand (WINZ).

Within the medical system, negative experiences related less frequently to individual practitioners although these occurred as well, but centred more around the multiplicity of assessments. Three of the participants reported favourably on their initial involvement in terms of the medical professions' examinations - two of whom still do.

The ways in which WINZ utilises this technology of power had varying impacts on the participants. At one end of the continuum is Daphne's assessment of 'impersonal form filling' (for National Superannuation) which she avoids 'to the last day, the last minute even' because she finds it intrusive.

At the other end of the scale is Josetta's experience of applying for an Invalid's Benefit and being turned down because WINZ did not accept she was 75% disabled. She appealed their decision, and as a result

I went in front of a panel of three different doctors... they took one look at me... they couldn't understand why WINZ had turned me down - and I was 85% disabled when I walked out of that place.

On reflecting back on this experience, Josetta added:

*It sucks basically because I had to... prove that I was disabled enough to get enough money to live on. It was horrendous, it was probably one of the worst experiences of my life. Another one... ...when I have to fill out forms for WINZ to prove I'm still disabled enough to qualify - **every year...** as if it's [MS] going to float away and disappear off you know - **come on.***

Marie's experiences of WINZ involve the intrusiveness of the gaze into her personal life. She has chosen to tell very few people she has MS. Because she is in receipt of the community wage (as a solo parent) she experiences pressure to work. As she is working part time to her physical capacity, she then has to explain her situation. Marie finds that this

...really annoys me to be sitting here in a position where I haven't told my friends I've got MS, I don't tell my acquaintances, but I have to tell an eighteen to twenty year old person whom I've never met in my life...

Both Josetta and Marie commented on the frequency with which case managers change or the frequency of change within the department itself, which means they must continuously restate their subject positions. This issue is reflected also in the comments made by two of the participants around frequent changes within the health system, and in terms of reassessments for care.

While two of the participants found the assessment for care was a positive process in that they were seen at their homes and felt that the assessors were genuinely trying to ensure they got the help they needed, Natasha found it an unnecessary and fragmented process, as she had already been assessed by the physiotherapist, and a further assessment was not needed, particularly as the assessor admitted she couldn't 'overrule' the physiotherapist's assessment anyway.

Discipline: Women with Multiple Sclerosis as subject / object of knowledge and power

The technologies of power, drawn together in the experiences of these eight women, combine to create their subject and object positions as Women with Multiple Sclerosis, knowable through discourse and power. In terms of their experiences of discipline as subject / object of knowledge, the following themes emerged:

- Issues of knowledge as power - including medical gatekeeping of knowledge about diagnosis and treatment, or alternatively,
- The use of 'professional' knowledge to 'discipline or undermine that of the participants - what Foucault terms the 'subjugation of knowledge' (Foucault, in Gordon, 1980).

The participants' experiences of gatekeeping of knowledge included not being told immediately of their diagnosis (four participants) and not being adequately informed about treatment options or being given treatment without being informed of its side effects (three participants).

The use of professional knowledge to discipline or undermine that of the participants included such actions as actively 'rubbishing' or invalidating their own research and knowledge bases, and not seeking their own expertise about their disease (four participants). Two participants described not being 'heard' by medical personnel and a further two found their specialist's use of clinic time to read their notes in an attempt to remind themselves of who these people were unhelpful and disempowering.

Two of the participants however had opposite experiences. Both received good information at the time of diagnosis, both were treated as part of a team of

professionals managing the disease and both were not only heard and validated in the clinic setting, but their own knowledge and expertise was sought and respected. Of the remaining six participants, one was able to develop a knowledge sharing relationship with her Naturopath, while others developed similar working relationships with their General Practitioners (two participants), or with a physiotherapist (three participants) who shared their expertise and sought that of the women.

Five participants described situations of being 'disciplined' by professionals. Kate, on informing her specialist that she could not self-catheterise due to paralysis in one hand and tremors in the other was told:

'Well, you have the intelligence to know that if you did that (self-catheterisation) you would be much better off... make an effort to do it'. She adds, It made me feel... stupid because I couldn't do it.

On another occasion, Kate was late to an appointment as her caregiver was late picking her up and couldn't locate a carpark. As the last patient for the day, she arrived to be told,

'You're late... I can only give you five minutes'... He was actually very rude. I thought, I've often waited for you for over an hour...

Following her apologising (without explaining her reasons) the specialist saw her for half an hour.

Such discipline also exists in other areas. Marie applied via her General Practitioner to the Health Funding Authority (HFA) for Exceptional Circumstances funding for the unsubsidised medication she takes to relieve her neuralgia. On being turned down by the HFA, she approached them directly to query the decision, and received a very terse response [sighted] that they

communicated directly with the General Practitioner. Josetta experienced a sense of intimidation at WINZ' communication around her appeal to obtain the Invalid's benefit.

Rebecca fought a long and hard battle against the medicalised response of her employer's insurance company who refused to pay out her insurance when she could no longer do her job, because of a typing error in her neurologist's report which created a 'ritual of truth' that didn't exist. Natasha's daily experiences of discipline within her former workplace became so abusive to her that she resigned her position.

These and other forms of discipline constructed within the technologies of power all served at times to maintain this group of women in their 'subjection'. For some of the women, their response to such technologies of power was to resist. For others, the discourse became internalised.

The internalised discourse of the disciplined individual

The results of the data obtained from the participants' narratives suggests a complex interaction of internalised discourses which supported the 'permanent economy of power' and discourses of resistance which included strategies of self-validation, questioning the knowledge and power of others or taking action as a form of protest.

In analysing the number of positive and negative responses, a trend began to emerge whereupon those participants with the fewest number of internalised responses and the highest number of strategic responses (with one exception) were the participants who had developed equal working relationships within their medical team, worksite and had access to information. In addition to this, while both participants had experienced the technologies of power, they also

described having access to alternative discourses and both were open about informing others they had the disease. Of note is that both these participants were also being treated with Interferon Beta.

The exception to this was Kate who, while she used multiple strategies to validate her own 'truths' and expertise, was in a position where she experienced ongoing difficulties with the technologies of power. That is, despite her being able to identify when she was being treated in a disciplinary manner, and while she resisted this treatment in terms of her own internal discourse, she also felt she didn't know the 'systems' well enough to protest or to prevent such treatment recurring. While her situation therefore does not reflect the responses noted in the data, it does indicate she has resisted internalising the discourses of discipline.

Three participants had responses where internalised discourse outweighed the discourses of resistance. Joesetta had internalised much of the discourse she had experienced from multiple professionals to the extent where she described herself as being 'too scared to basically do anything'. She made several references to appearing 'normal', as did Debbie who also scored in this way. Marie, while having access to an alternative discourse in her sister's responses to having MS, chose to not tell people she too had the disease. These three women to varying degrees had 'hidden' impairments, which could be a factor in these responses. Daphne mentioned only two responses which are interpreted as internalised discourse, and these occurred very soon after diagnosis some twenty-six years previously. She then had access to disabled mentors who exposed her to alternative discourses.

Maxine's responses were evenly spread. She has experienced similar supports to Natasha and Rebecca and has a similar outlook to them. However, in recent

years she has experienced the technologies of power from two agencies particularly and additionally, has struggled to gain employment. Despite having the skills base and an excellent work history, after almost sixty job rejections, she is beginning to internalise the discourse of normalising judgement, suggesting that she should begin 'aiming a little more lowly'.

This data suggests that further exploration is required to ascertain at what point the internalised discourse of the disciplined individual overrides the discourses of resistance in order to develop an awareness of the 'risk' of internalising discourse. It seems that Maxine may be at risk of doing so at the expense of her own well established discourse of resistance.

THE MEDICALISATION OF DISABILITY AND MULTIPLE SCLEROSIS

The experience of medicalisation of disability varied across the group, with a total of thirty-eight responses describing medicalisation at a variety of social levels. These responses varied from being told to

make the most of your life because you will end up in a wheelchair (Debbie)

- within weeks of diagnosis; to Maxine being told by the director of a computer course run through an agency for disabled people she was unlikely to get another job because of her disease. All of the participants had, at some stage faced a 'personal tragedy' response from others, although the degree to which this happened varied across the group.

Demedicalisation of Multiple Sclerosis?

As mentioned earlier, the issue was raised that medicalised 'labelling' of problems can be beneficial. For five of the women in this study, being diagnosed (or 'labelled') was important to them. For some, the alternative

possibilities (that they had a life-threatening disease) were more frightening. For others, finally getting a diagnosis stopped them from being labelled as lazy, neurotic, hysterical, menopausal or mentally unwell. Several of the women had begun to believe they were mentally ill, so the diagnosis brought relief in a sense, that they weren't imagining their odd collection of symptoms.

All of the women had, at points in their lives with MS, depended heavily on the medical profession for treatment. As Multiple Sclerosis is a disease, this would seem entirely appropriate. Once the women established a relatively stable regime around the management of their disease, they each had reduced their involvement with these professionals. This too would seem appropriate.

I contend that it is at this point where it becomes appropriate to explore the alternative discourses available to impaired people - to begin to differentiate between what is a medical problem and what issues belong to society. That is, the experience of Multiple Sclerosis can be demedicalised while holding in tension the demands of the medical requirements of living with an unpredictable disease.

The Remedicalisation of Multiple Sclerosis?

I have already raised the issue of a remedicalisation of disability as an emergent theme within this study. Two of the participants are using Interferon Beta, one of whom was funded for two years through her local MS Society (now State funded) and one who began State funded treatment this year.

One of the participants is in the process of applying for funded treatment, which has meant that after almost nineteen years of having little to do with the medical profession, she had to re-enter a system which in the past was not positive for her. When I contacted her to check the accuracy of her transcript,

she reported that this experience was also not a positive one. She still received little information (as had happened at the time of her diagnosis), the specialist she saw lost her notes and had to start again, and she was left distrusting him to complete the application for Interferon Beta - yet, in a subject position, had no choice but to do so.

Marie has also had little to do with the medical system, and tended to manage any exacerbations of MS herself without seeing a doctor. Now, in order to 'qualify' for treatment with Interferon Beta, she has to present herself for 'confirmation' of each flare up (hierarchical observation), then be assessed as to her disability level (normalising judgement and examination) prior to being able to apply for the treatment.

CONCLUSION

This chapter set out to examine from a Foucauldian perspective the medical framework which encapsulates people with Multiple Sclerosis. Foucault's technologies of power have been presented along with discussions on the subject/object experience of knowledge and power, and the internalised discourse of the disciplined individual. The medicalisation of disability was revisited, along with some of the issues such an approach raises when applying it to a disease such as Multiple Sclerosis.

The experiences of the participants of this research have also been presented, which suggest that the responses of the group in this study supports Foucauldian assumptions that technologies of power exist in such a manner as to create a negative subject position for this group of women with Multiple Sclerosis. This is however a somewhat tenuous position given that the ratio of negative to positive responses is not markedly different.

Also revealed were some counterbalancing effects of resistance, multiple strategies and alternative discourses. Emerging from this is the suggestion that further exploration is required of the process of internalising discourse, as a means by which to identify when someone may be at 'risk' of internalising oppressive discourses, and from this, establishing strategies for empowering disabled people to access alternative discourses and strategies of resistance.

Another emergent theme which suggests the need for further research is that of the remedicalisation of disability in order to access disease-altering treatment. The ramifications of living with an unpredictable disease **do** at times require medicalised intervention. The ramifications of living in an unpredictable, economy driven climate in which treatment, care and welfare 'choices' lie within a medicalised framework requires a different approach. One such approach will now be explored further.

CHAPTER SIX: OPPRESSION? THE SOCIAL MODEL OF DISABILITY AND MULTIPLE SCLEROSIS

INTRODUCTION

The previous chapter provided a Foucauldian analysis of the technologies of power which create and maintain certain subject positions, particularly in terms of the medicalisation of disability and the experiences of the participants in this study. Within that chapter I suggested that there was a point at which it became appropriate to explore the alternative discourses available to differentiate between what (in the case of Multiple Sclerosis) is a medical concern, and what issues belong to society.

This chapter explores further the social model of disability as one such alternative. The social model of disability is firstly discussed, followed by a description and analysis of the experiences of the research participants in relation to this theoretical approach. Finally, I will discuss further some of the debates raised within the Literature Review, particularly in terms of the need to recognise the 'downward trajectory' (Lonsdale, 1990) of a disease such as Multiple Sclerosis.

THE SOCIAL MODEL OF DISABILITY

The development of the social model of disability

As previously discussed, it is perhaps the work of Michael Oliver which is most frequently associated with this model. Oliver, a well-published academic, developed his interests in disability on beginning university studies some ten years after he broke his neck. He discovered, on reading what able-bodied academics, professionals and researchers had written about disability,

- how little it related to my own experience or... that of most other disabled people I'd come to know (Oliver, 1996:9).

Coupled with his experiences of disablist attitudes and difficulties with physical access to buildings within the university setting, Oliver began to seek and develop alternative understandings of the concept of disability, beginning with the profound redefinition of disability presented at the beginning of this thesis. Oliver asserts that

While it cannot be claimed that there has been much grand theorising about disability, it can be argued that almost all studies of disability have a grand theory underpinning them. That grand theory can be characterised as the 'personal tragedy theory of disability' (1990:1).

The ways in which disability is defined is important in that human discourse develops an entire world of meaning and behaviours around those definitions. As W.I. Thomas (1966) suggests:

If men [sic] define situations as real, they are real in their consequences.

With this in mind, Oliver argues that if disability is viewed as a personal tragedy, then disabled people will be treated as victims of unfortunate circumstances; as such discourse develops, it is translated into social policies which 'attempt to compensate these victims for the tragedies that have befallen them' (1990:2). For example, within the public transport system, a disabled person's inability to travel by bus is perceived as being caused by their impairment alone. A form of individual compensation is to issue them with taxi vouchers. To obtain such vouchers however, one must face hierarchical observation and normalising discourses which define the problem as being located within the individual.

However, if disability is defined in terms of social oppression, then discourses of disability perceive disabled people as 'collective victims of an uncaring or unknowing society' (Ibid:2). Social policies underpinned by this alternative view

are therefore focused on alleviating oppression instead of individual compensation. As an example, within the public transport system such an approach focuses on the development of policies which ensure accessible buses are provided for the whole population to use.

In individualising disability as a personal tragedy, the social model argues that disability becomes medicalised, producing definitions that focus on the pathology of the individual. Oliver argues that

this medical approach produces definitions of disability which are partial and limited and which fail to take into account wider aspects of disability (1990:5).

Such an approach not only applies to the definition of the 'problem' of disability, but is also reflected within the 'solutions' applied - the services and policies created to address disability, which Oliver debates

are based upon an individualised and medicalised view of disability and are designed by able-bodied people through a process over which disabled people have had little or no control (Ibid:6).

Powerlessness and worthlessness: The discourse of personal tragedy theory

As previously discussed, Barton (1992) perceives disability as a 'social and political category', which results in people experiencing

powerlessness and worthlessness in an alien society (1992:15).

If discourses of disability perceive disability as personal tragedy, then one can analyse and identify such discourses from a multi-level perspective - from Foucault's internalised individual discourse to the responses of family and friends to the news of impairment. Furthermore, this analysis can then also be applied to the discursive practices of places of work or study, agencies and the

wider community, through to the impact of societal discourses and the social policies which reflect them.

For example, how those closest to an impaired person manage firstly the news that a person has become (or in the case of a disease like MS, is likely to become) impaired can immediately confirm to that person that their experience is a personal tragedy, and that they have somehow diminished in worth as a consequence. Following the initial news of impairment, the responses of family and friends can be further analysed as to how they restructure themselves in order to ensure the impaired person is supported to maintain a valued role or roles within their inner circle, or if the 'problem' of impairment begins to be individualised as something which decreases their worth in the eyes of those closest to them or if they begin to experience powerlessness within this setting.

Within the work or education setting, analysis using the social model of disability focuses upon the worth placed upon impaired employees and the ways in which they are supported to continue their roles within the work environment or to achieve study or training goals. Oliver debates at length the ways in which the rise of capitalism has served to exclude disabled people from the production process (1990) the outcome of which is that they are less likely to become or remain employed, which decreases their economic power. He also argues that the education systems, particularly for disabled children and young people serve to segregate them and fail to adequately provide them with skills for daily living, a concern echoed by Keith Ballard (1992).

A social model analysis also examines the ways in which the broader community, including agencies and charities medicalise disability. In so doing, this model critiques the ways organisations 'for' disabled people support the current views of disability as personal tragedy (Oliver, 1990; Morris, 1991)

which disempowers disabled people and confirms to them that they are of less worth than their non-disabled counterparts; as compared to the more political focus of organisations 'of' disabled people.

At the societal or policy level, a social model analysis examines how policies developed within an underpinning discourse of disability as personal tragedy fail to meet the needs of disabled people, and rather than ensuring adequate and equitable provision of services, further devalue and disempower them.

Disability as social oppression

While Barton presents the concepts of powerlessness and worthlessness as the experiential aspect of the social model critique, as social oppression the model locates disability within

a society that imposes material, social, psychological and environmental constraints upon people as 'discrimination' (Morris, 1991) and social oppression (Oliver, 1990, 1992).

What this means is that in redefining what happens to the body as **impairment**, and the oppressive structures of society as **disability**, the societal structures that disable can be more easily identified and critiqued, allowing for the development of a politics of resistance and change.

At times these structures are clear; an obvious example of such a critique is that it is not the use of a wheelchair for mobility that constitutes 'disability', but the environmental barriers of inaccessible buildings, curbs and steps which exclude wheelchair users from accessing their environment as freely as their non-impaired counterparts.

Material constraints may be viewed as the ways in which inadequate or poverty line welfare provisions reduce the economic power of disabled people to such a degree that they are unable to exercise freedom of choice in the marketplace. This may include not being able to afford an adequate diet or medical care. The outcome of such a situation is that the societal structure can impact upon an impaired person more significantly than their impairment does; poor diet and inadequate healthcare places an additional burden upon the lived experience of impairment.

Psychological constraints may include being met with stares, having privacy intruded upon by personal questions from strangers about one's impairment, or open hostility when out in public; all of which serve to undermine a disabled person's sense of worth and identity as a valuable member of their community. Non-impaired individuals seldom face such intrusiveness, yet these sorts of psychological constraints are faced daily by impaired people.

Psychological constraints can also include subtle or overt pressure within a workplace to leave paid employment, or to reduce working hours to allow for the employment of an 'able-bodied' person instead. At its extreme, open hostility and abuse can impact on disabled people to the extent that they can not manage the psychological pressure of such oppression and withdraw.

Empowerment and resistance: A politics of change

In redefining disability as social oppression and locating the 'problem' of disability as either in the minds of individuals (prejudice) or collectively within the responses of society the tragic view of disability is thus deconstructed, allowing for the emergence of alternative discourses and a politics of resistance and change from the level of the body to the level of society and social policy.

In challenging what occurs to the disabled body, the social model of disability questions the necessity of doctors treating disability rather than illness through medical interventions or of multiple medical assessments for social assistance.

As Oliver asserts:

Disability as a long term state is not treatable medically and is certainly not curable. Hence, many disabled people experience much medical intervention as at best, inappropriate, and, at worst, oppressive (1996:36).

In examining the impact of social policy, Oliver (1990, 1996) discusses the rights of disabled people in terms of citizenship, the denial of basic human rights to adequate economic security and the concept of civil rights. He draws upon Marshall's (1952) broad definition of civil rights to include legal rights and also those of freedom of thought, speech, assembly and association. Debating that the rights (and duties and obligations) of citizenship are also influenced by current ideologies of individualism and economic liberalism underpinned by the medicalisation of disability, Oliver argues that the State (in his case, the United Kingdom):

has not only not ensured the citizenship rights of disabled people, but through some of its provisions and practices it has infringed and even taken away some of these rights (1996:52).

As examples, Oliver cites the loss of privacy disabled people endure to obtain aids for daily living, and the segregation of disabled people in residential facilities, while Oliver and Barnes (1991) debate that despite a comprehensive 'legal' framework for provision of services to disabled people, the services needed as a basic human right 'somehow do not get delivered' as the definitions of human 'rights' become subverted within Libertarian definitions of 'need'.

THE SOCIAL MODEL OF DISABILITY AND THE EXPERIENCE OF MULTIPLE SCLEROSIS

Data Results

Two key concepts were examined within the data in this study in terms of the social model. These were the experience of powerlessness or worthlessness, and the experience of disabling material, social, psychological and environmental constraints which oppress disabled people. As far as the experience of powerlessness or worthlessness was concerned, data was coded according to participant references to situations in which they experienced a loss of power or autonomy; or where they were perceived or perceived themselves as having less or no worth within the context they described.

With regards to the experience of disabling constraints, data was coded by applying the theorists' definition of such constraints to the situations described by the participants. This definition is discussed further later in this chapter. The following results were thus obtained:

Figure 6.1: Participant references to the Experience of Powerlessness or Worthlessness and the Experience of Disabling Constraints as Social Oppression.

Name	Powerlessness / Worthlessness	Disabling Constraints	Total
Daphne	2	0	2
Debbie	12	7	19
Josetta	27	11	38
Kate	29	13	42
Marie	12	5	17
Maxine	14	8	22
Natasha	39	21	60
Rebecca	3	2	5
Total	138	67	205

Participants also referred to experiences in which they felt valued and experienced empowerment. Therefore the data was also analysed in terms of

the presence of such experiences, and that of enabling material, social, psychological and environmental assistance as a form of social emancipation for these women. From this analysis, the following results emerged:

Figure 6.2: Participant References to the Experience of Empowerment or Being Valued and the Experience of Enabling Assistance as Social Emancipation.

Name	Empowerment or Value	Enabling Assistance	Total
Daphne	11	5	16
Debbie	12	2	14
Josetta	10	5	15
Kate	8	2	10
Marie	12	1	13
Maxine	14	4	18
Natasha	22	9	31
Rebecca	13	5	18
Total	102	33	135

The participant references to experiences of powerlessness or worthlessness as well as to those of being empowered or valued were further analysed to identify at what levels of society these experiences occurred. This produced the following results:

Figure 6.3: Participant References to the Experience of Powerlessness or Worthlessness at Different Societal Levels.

Name	Family Level	Community Level	Societal Level	Total
Daphne	1	0	1	2
Debbie	5	5	2	12
Josetta	7	16	4	27
Kate	9	12	8	29
Marie	4	4	4	12
Maxine	1	7	6	14
Natasha	4	26	9	39
Rebecca	1	0	2	3
Total	32	70	36	138

The participants also related incidents in which positive experiences of being or feeling empowered or valued counterbalanced or outweighed the impact(s) of the above negative experiences.

Figure 6.4: Participant References to the Experience of Empowerment or Being Valued at Different Societal Levels.

Name	Family Level	Community Level	Societal Level	Total
Daphne	2	7	2	11
Debbie	9	3	0	12
Josetta	4	5	1	10
Kate	4	1	3	8
Marie	6	5	1	12
Maxine	6	7	1	14
Natasha	7	14	1	22
Rebecca	7	6	0	13
Total	45	48	9	102

Finally, the data was also coded for the presence of strategies and resistance in terms of a 'Politics of Change' which is discussed within the Literature Review. The results of this analysis were:

Figure 6.5: Social Oppression Theory: Participant use of Strategies and Resistance and a Politics of Change.

Name	Strategies/Resistance	Politics of Change	Total
Daphne	9	0	9
Debbie	20	1	21
Josetta	17	4	21
Kate	23	4	27
Marie	5	2	7
Maxine	15	6	21
Natasha	53	3	56
Rebecca	15	0	15
Total	157	20	177

DISCUSSION

The experience of powerlessness or worthlessness

Family/Friends Level

At the Family level (which includes friends), experiences of powerlessness or worthlessness ranged from the expression of friends' or family members' own 'personal tragedy' response (six participants) to one participant feeling so disempowered or 'disabled' by her family's responses to her disease that she moved to another city. Alternatively, friends or family offered advice which was disempowering, in that they suggested the women stop activities which were important to them. For Marie, who faced such a response, this meant:

You can't say you're tired around people like that - that [response] takes away a bit of your person...

Marie had the added difficulty of her husband's ethnic and cultural belief system being:

You are in control of yourself - climb over this. It's hard for him to accept that this is a disease, you can't climb over this, it's always going to be there.

Five of the participants, while experiencing negative events of powerlessness or worthlessness at this societal level, reported more positive events than negative. Many of these centred around maintaining active and valued roles and relationships with family and friends, as well as their responses not reflecting a personal tragedy response.

Community Level

At the community level, experiences of powerlessness were at times far reaching for six of the participants of this study.

Work/Education

Five of these six participants were working or studying full time at the time of and following being diagnosed with MS. Josetta, who was studying full time, noticed that she was struggling to keep up with her studies due to a combination of cognitive dysfunction and the speed at which information was delivered within her course. There was little opportunity within her tertiary course for her to take the course at a much reduced pace:

...they [tertiary institutions] feed it to you so fast and you've got all this info and it's horrendous....I just reached the point where I felt, if I stay in this, I'm going to top myself... so I had to withdraw from study, I just couldn't take it any more.

Natasha also studies at a tertiary level, but does not experience Josetta's difficulties with cognitive dysfunction. She has however been well supported by her university when, due to visual disturbances she has required additional time to complete work.

Maxine had been working successfully in the same job for almost fifteen years, where her MS, her impairment and occasional needs for assistance had never been an issue for herself or her colleagues. A year and a half ago, a new director was appointed to the organisation who, within a short space of time, approached Maxine and said, 'You don't fit in do you dear?' Within weeks he restructured her job description to be very computer loaded, which was problematic for her, due to loss of sensation in her fingers.

Over a period of a few months, he sent Maxine a series of aggressive, threatening memos [sighted] in which he created a 'ritual of truth' that not only was she unable, she was unwilling to use the computer; creating this as a disciplinary matter. She was given little opportunity to defend her position as her hours were firstly reduced, then her position disestablished. While Maxine

was unsure if his response was due directly to her impairment, she felt powerless within the situation.

Natasha faced opposite extremes in responses within two workplaces. Shortly following being diagnosed, she

was asked to meet with my manager and supervisor - immediately. I had no time to organise a support person to be with me, and as soon as I confirmed that I had MS, I was given instructions to accept a contract for half time work with no sick leave provisions... I was devastated... that within the space of a week I'd become only good enough for half time work...

Natasha later describes this response as:

...the beginning of what became to me, a matter of survival in what felt like a 'cold war' zone

- in which she was expected to maintain full time work on half time hours, faced multiple negative responses from management on a daily basis and felt set up to fail. While her colleagues supported her, she felt they were as paralysed as her by the situation. Natasha's current worksite has been an 'entirely opposite experience', in which her new manager

was left in no doubt about what could happen [regarding her MS]. Her response was positive, proactive and tremendously empowering.

A contract was set up for Natasha which took into account her needs and supported her within her workplace and around her study goals.

Debbie has recently begun to experience some difficulties with attitudes towards her impairment becoming more obvious (which hasn't affected her outputs), particularly the suggestion being made that she should accept a

demotion (and with that, a cut in pay) which lowers her worth. This is not something she wants to occur, but coupled with her inability to attend regular training to update her knowledge base due to an inaccessible training venue, she is beginning to foresee this happening. As a result, she is seriously considering resigning her position.

Daphne and Rebecca have both had very positive experiences in which their worth as employees has not been in any way undermined. Daphne worked in several different positions, including within the disability sector, and was not subjected to discourses in which her worth has been questioned. Similarly, Rebecca works within an industry which she defines as being 'very black and white'. Her employers are aware she has MS and have a 'good attitude'. As a result, she has no qualms about requesting help when she requires it.

Community/Community Agencies

The responses experienced within their communities were again varied and frequently complex. Five participants commented on the ways in which they were asked by strangers what they had 'done to themselves' if seen out using walking aids, or if limping. Two participants who use wheelchairs talked of being shouted at as if they were hard of hearing, or treated as if not present - by talking to their companion (Natasha), or 'simple' (Kate). Participants at times described an uneasy resentment at being asked what was 'wrong' or what they'd 'done' to themselves, finding these questions sometimes reflecting genuine concern, at others, intrusive.

The participants had a variety of responses to such enquiries, alternating between telling people to 'mind their own business', telling them they had MS:

I just tell them the truth, it's not actually [an issue]. I have fairly strong opinions in that I don't think people do any benefit to a condition like this by covering it up' (Rebecca).

or alternatively, turning the situation back on the person who asked, as Maxine describes:

I say, 'I have done nothing to myself, it has done it to me!' Maxine later adds, I don't know, I might be very mean when I turn it on the head like that, but I just feel the need to say 'I didn't do anything'...

Marie prefers not to tell people she has MS, and uses a variety of management strategies to continue to work part time while coping with fatigue and the ongoing pain of neuralgia. She has told only a few people outside her family, and has regretted doing so each time, as:

You can't un-tell people - once you've told them, it's there, it's there in their minds; I don't want to be 'Marie with MS'.

Marie also does not apply for jobs where she has to disclose her medical condition because she believes that the positions will be given to someone else, confirming to her that she is of less value within the job market. Natasha experienced just this situation prior to being diagnosed. She applied twice for a position in a large healthcare organisation: once under her maiden name (when she didn't have a medical condition), and one in which she disclosed her currently being investigated condition. Her maiden name application got an interview, while the other didn't. When she challenged the organisation about this, they became very defensive. Marie's response therefore may be an astute assessment of the current job market or alternatively, of the difficulties of ensuring Equal Employment Opportunities policies are actioned.

Care or home assistance agencies were alternatively viewed as being positive in that the services provided enabled two of the women to continue living a full life; or 'regulatory' in nature (one participant) as they weren't flexible in their provision of care. Two of the women critiqued the low wages paid to caregivers and questioned the 'worth' such low pay reflects on the recipients of care. One of the participants had been allocated home help hours, but had withdrawn from receiving them as she felt that nobody would want to clean her home due to having dogs, being unhappy with the standard of cleaning and resenting having people 'parading' around her private space. She did admit that when she had this assistance it enabled her to participate more in other areas of her life.

A variety of community disability support agencies had been accessed by participants in this study, including disabled employment and supported employment agencies, disability resource centres and disability organisations such as the Disabled Person's Assembly and the MS Societies in the participants' regions.

Again, the experiences of the participants varied, although the two participants who were initially involved with an employment agency for disabled people both later became involved with a supported employment agency. As Maxine describes:

I was involved at [employment agency] ... but opted to cut my ties from them because they didn't have a very positive attitude... like I'd go to an appointment with her... and she'd have me in tears every time...

Whereas at the supported employment agency:

She's had a totally different 'can do' attitude, which I think is for me... the only way I can cope with life in general...

All of the participants except Daphne belonged to or had been members of their local MS Societies. Daphne did not join:

I have no wish to sit around comparing symptoms...

- but for a time joined an Australian branch of the MS Society, and is involved in the Disabled Person's Assembly. Three of the participants utilised the society primarily in order to receive its newsletter or information, although one of the women critiqued the National Society's newsletter as being full of 'the search for the cure' rather than 'how to live with MS now'.

A review of the NZMSS journals over the past three years did not necessarily confirm this statement - but what **was** apparent is that over the past eight issues of the journal, is a shift to articles with a much more medicalised focus on research and drug treatment of symptoms (31 in 2000; 30 in 1999 compared to 18 in 1998 and 12 in 1997) than the previously broader focus of the eighteen months prior which included comparatively more activities people with MS could undertake themselves to manage their disease. This shift is disturbing, as it may well reflect the 'remedicalisation' of the disease discussed in Chapter Five.

Also noted was that the reviews of research being conducted into Multiple Sclerosis (included in the journal as a lift out section) very rarely referred to social research and never referred to socio-political studies being undertaken. This means that people with MS are not being exposed to alternative viewpoints through their National Society, but may also reflect a further criticism levelled at the society at the National level - that they were 'not political enough and are too busy playing the government's games' [around equitable subsidisation of Interferons].

At the local level of involvement, one of the above participants also knew she could make contact with the local MS Society if required and occasionally did so. For another participant however, this arrangement was problematic as she was reluctant to 'trouble' the Society's field officer, yet felt 'peeved' that in the past three months she'd heard nothing from them, saying:

Maybe I need to get on the phone and say, 'Hey, I need to be acknowledged here, that I still exist you know, have you forgotten that I'm even here?' (Name withheld to protect privacy).

Kate found her first meeting with a new field officer disempowering:

She kept standing behind me and I said 'please come around... I can't turn my head around' [The worker was standing behind Kate, toasting herself by the heater]... I couldn't talk to her - I spoke to the wind, I spoke to the door, she'd talk behind me.

Natasha found meeting with others with MS through her local Society encouraging as they shared helpful advice about managing the disease. She was later funded for treatment with Interferon Beta by her local Society as the rapid progress of her disease meant the treatment became her only option available for slowing down the disease process - at that stage it was not funded by Pharmac.

Societal/Social Policy Level

The issues raised in the previous chapter regarding welfare agencies such as WINZ are also examples of the social model of disability where social policies, underpinned by medicalised discourses of power are hostile to impaired people, and fail to deliver adequate resources when needed. But, as Foucault asserts, such technologies exist within historical contexts, and Daphne's experience is an example of a person placed in the right place at the right time in terms of welfare provision.

Daphne has twice received suspensory loans through the former Department of Social Welfare during her life with MS to purchase modified vehicles which enabled her to 'obtain or retain work'. A week before she retired, Daphne was asked to work part time for a community agency, which meant she met the criteria for her second suspensory loan and obtained a new modified vehicle which enabled her to remain involved in her community after retiring.

Her birthdate enabled her to retire on National Superannuation with thirteen days to spare - policy then changed the age of retirement to 65 years. Daphne also receives three hours per week home help which gives her further freedom. For Daphne, who at the age of 68 remains involved in a multitude of clubs and organisations :

*...believe me, retirement is a brilliant time of life, when you have **choice**.*

Kate, at the age of 60 (although her impairment level is much higher than Daphne's) has it could be argued, experienced the opposite that social policy has to offer. She is not entitled to National Superannuation, and while she receives home help and personal care twice daily her experience has primarily been one of the clawing back of the welfare state.

Her home is wheelchair inaccessible, and to access her toilet she must leave the door open, denying her privacy [unfortunately observed when I arrived to interview her]. When asked about this issue, Kate acknowledged that her home was 'totally unsuitable', and she was likely to move in the future - which was why, despite needing alterations, she would not do them. The funding for such 'assistance' is arranged so that she becomes tied to her home for a minimum of five years. Regardless of changing needs, she would get no further assistance if she had to move.

This was an issue which impacted on Natasha. After having a waterlift installed for wheelchair access to her home, Natasha had to move house six months later. The waterlift was not required at her new home, so went, at little extra cost to another person. But, Natasha was informed she was no longer 'entitled' to access assistance for a further five years.

Maxine requires a mobility scooter, but with only her husband's income, can not purchase one. She has applied to the Lotteries Commission for funding, but has been told that due to her husband's income (regardless of their outgoings), she is unlikely to receive this assistance. This means she will continue to be unable to visit three houses down the road where she supports an elderly friend - both women therefore miss out.

Maxine is currently seeking employment, and has become eligible for Mainstream Employment Funding, a government initiative for long term unemployed disabled. Once approved, there are listed [sighted] employers who, by creating a position for a disabled person, can access this funding. For the first year of employment, the State pays the employee's wages, reducing by half the following year the other half paid by the employer; and then:

hopefully by year three you will have made yourself so indispensable, they will pay the lot...

However, despite a large list of employers able to access this funding, their response is:

..'we can't afford a new position', to which [supported employment worker] said, 'hey, you aren't paying for it in the first year, you are only paying for half in the second year'. [They respond] 'Oh, but what about the third year?'

Maxine is well aware of the commodification of self in this process, saying:

Theoretically I should be the most marketable person in the [region]...and, now approved, it's [supported employment agency's] job is to sell me.

Despite policy attempting to support inclusion in the workplace, after almost sixty job rejections, it would appear that the listed employers **able** to engage in this initiative are not, in practice, **willing** to do so for Maxine. Her own comment below summarises this well:

That's where the Mainstream fits, yes, that's the Mainstream...

Josetta's difficulties with WINZ have been discussed; she fears further physical deterioration as she knows that her husband and family won't assist her, and fears that the State won't either.

Natasha and Rebecca are in receipt of State funded Interferon Beta treatment, and both have experienced benefits from it. Debbie is in the process of applying for it, and said she would be 'gutted' if she didn't get funded as her MS is beginning to progress more rapidly. To date she has needed no assistance from the State, and her future health now depends on the provision of very limited supplies of funded medication.

Natasha, while having made remarkable progress on Interferon, fears that she may develop neutralising antibodies to the agent which is an exit criteria set by Pharmac despite research (Herndon et.al., 1999) indicating such antibodies can also decrease or disappear with continued use of (in this case, Interferon Beta 1a). Natasha may therefore have no **choice** about remaining on the treatment. Kate was advised that if she could pay for treatment, it would be given to her, but as she has secondary progressive MS, she was not 'worth the

investment'; again, despite research indicating otherwise (see NZMSS,1998; NMSS USA,1998; NZMSS, 1999 c).

The issue of funded medication is not only limited to that of these agents. Marie in particular has issues with a lack of funding for treatment of her neuralgia (severe nerve pain) with Gabapentin (an anticonvulsant also used for neuralgia) which is not subsidised by Pharmac. She mentioned several times that of all her symptoms, neuralgia is the one she most wants to do something about. She is currently on a very low dose of Gabapentin which is all she can afford (at a cost of \$160.00 per month) on Income Support, and, having tried all the other options available to her, the only one that has made a difference.

Her HFA application for Exceptional Circumstances funding was turned down on the grounds that her doctor wrote on her application that MS was a **common** disease, rather than uncommon; as a result, like Rebecca's experience with the Insurance Company, created a 'ritual of truth' that became impossible for Marie to override. While she is aware that another woman with MS went to the Paul Holmes show for this reason (and was rapidly funded), Marie is a very private person - for her, having to consider such action angers her:

Why isn't self advocacy enough? I resent the fact you should have to do that.

The process of appealing the HFA decision was so difficult that she withdrew. As a result, she is left in pain, unable to increase the dose of her medication because she can't afford it. Marie has fallen through the overstrung 'safety net' of a clawed back State. As a consequence of social policy hostile to the adequate treatment of her impairment, Marie is not considered 'worth' the treatment - and is currently powerless to do anything about it.

Disability as social oppression

All of the women in this study experience a variety of impairments as a consequence of having Multiple Sclerosis, many of which they manage without other people knowing, for example incontinence, pain or fatigue. But for all but one participant, the experience of physical, material, psychological or environmental constraints has or still compounds the impact of their impairment on them.

The previous social policy issues are examples of such constraints. Marie's **impairment** is neuralgia. The material constraints of unfunded medication prevent her having adequate treatment. The psychological constraints of dealing with a hostile funding authority caused her to withdraw. These constraints are **disability**.

Similarly, Kate uses a wheelchair and receives personal assistance because of her impairment. She is disabled by environmental constraints of an inaccessible home, further affected by material constraints of a policy that limits her choices around having her home made accessible.

Maxine's impairment prevents her from walking distances. But until she receives assistance to obtain a scooter, material constraints disable her from improved mobility. Her previous workplace imposed psychological and environmental barriers to her continued employment, then couched the problem in terms of her inability to adapt to a rapidly changed situation after a decade and a half of excellent work [references were sighted]. The apparently liberating Mainstream Employment Funding is not actioned by employers who put in place material and social constraints to both Maxine's continued employment **and** to the success of this policy; Maxine's impairment is not preventing her working.

Josetta experiences the economic oppression of a poverty line income (Invalid's Benefit) which barely meets her basic needs. For her this means she cannot afford to go out, even if using the taxi mobility scheme. Buses are environmentally constraining - she cannot access them, so her social and leisure pursuits are restricted. Coupled with her 'invisible' impairments of cognitive dysfunction and a severe mood disorder, she has become socially isolated in her home. As Josetta recognises:

*So even though I'm not on elbow crutches shuffling anymore,
it's like I still am.*

Natasha experienced physical, psychological and social constraints within her former workplace which made her work impossible to do. She now experiences the opposite, and as a result, can continue to work full time despite physical impairment. Debbie's impairment means she can not climb stairs - her employer's training venue requires she climb two flights of stairs, an environmental constraint which prevents her from attending and increases her vulnerability of demotion.

Rebecca's Insurance Company difficulties exposed her to a multilevel system of social and psychological constraints as they attempted to 'redesign' her as mentally ill, refused to give her copies of information and used biased appeal processes. It was only Rebecca's sheer determination and resistance to this discourse of oppression that enabled her to obtain what was essentially her right.

Empowerment and Resistance: A politics of change

Rebecca's battle with the Insurance Company is one example of resistance to oppression. All of the participants have made use of a variety of strategies of resistance to manage their experiences at each societal level. These

responses range from the level of discourse, by self-validating one's experience as 'real' or existence as valuable (all of the participants); to challenging people's stares or comments in the community (three women); to taking action and complaining about treatment or identifying oppressive situations and demanding they be changed (five women).

Resistance to the 'personal tragedy' response features strongly within the responses of five participants, with four of them actively rejecting this discourse in themselves or others. These participants also have multiple social contacts who have supported them in resisting oppressive situations when they have encountered them. This is not to say that they have not at times succumbed to oppressive practices, but it does appear that non-acceptance of the personal tragedy theory offers these women the opportunity to better advocate for themselves and to recognise times when it is the social structure rather than their disease which is the problem.

It would appear that a politics of change emerges as such an awareness occurs; but that the development of such a politics is a slow process. Six of the participants were able to identify changes they needed at a personal level, also raising issues around access within their communities being inadequate for disabled people in general. Three of the participants suggested changes were needed at the State/societal level, but only one participant presented her information or suggestions in terms of her Civil Rights, although Marie's comment about self advocacy comes close to recognising the rights issue involved.

Daphne, on completing her interview, embarked on a lively discussion in which she critiqued the social model of disability. She had been exposed to some of

these debates, and commented that she did not accept the:

Chip on your shoulder, the world owes us politics.

While Daphne has worked for many years within the disability arena, her politics of disability does not include this theory of oppression.

The data results have begun to reveal an emerging trend whereby those participants with a low total of powerlessness and/or disabling constraints and high totals of empowerment and/or enabling assistance (Daphne and Rebecca) were those who were also the most involved within their community, workplace and/or family; and who also reported being most at ease with their current position.

Two of the participants had opposite totals where their reported experiences of powerlessness and disabling constraints outweighed those of value and assistance - these two (Josetta and Kate) are least involved in their communities. What must also be taken into account, which is discussed further in Chapter Seven is that these participants also have significant levels of impairment, although both identify that with appropriate assistance these might not be as significant as they currently are.

Three participants had results which had ratios of powerlessness and constraints higher than but similar to their experiences of empowerment and being enabled (Debbie and Marie both have ratios of 1.3 to 1, while Maxine's was 1.2 to 1). Of note is that Debbie and Marie both use strategies to hide impairment, or of withdrawal in situations of powerlessness. Maxine rarely uses such strategies, but her experiences, particularly over the previous two years, have led to a gradual lowering of her aspirations despite her abilities. The impairment levels for these women are varied.

What these results may suggest is that it is possible to predict that high levels of powerlessness and low levels of empowerment could result in increased experiences of social oppression. Stemming from such a proposition, one could then explore the possibilities of developing strategies with women such as Kate, Josetta, Debbie, Marie and Maxine whereby access to an alternative discourse of disability may enable them to better challenge the discourses of oppression they encounter at each level of society rather than to internalise the discourse that disability is an individual problem.

Natasha's results skew the data somewhat - given that her experiences of powerlessness and constraints outweigh those of empowerment and enabling by a ratio of almost 2:1 and that she experiences significant impairment, one would assume, given the suggestion made above, that her experience would be similar to that of Josetta and Kate.

This is not the case however; most of the experiences she relayed occurred within the first year of her disease, and within one workplace. She had access to an alternative discourse to medicalisation, and utilised that to resist the oppression (defined by herself) she was experiencing. She is now experiencing a gradual increase in experiences of value and enabling in her new work environment, as compared to Maxine's gradual increase in the opposite experiences which, despite having an alternative discourse to medicalisation, is beginning to impact on her.

Access to alternative discourses featured for four of the women - Natasha and Maxine (above), and also Daphne and Rebecca. Daphne credits having two disabled mentors who challenged and supported her early in her disease, while Rebecca recognises that her lack of 'personal tragedy' responses has assisted

her in adjusting to having MS:

I think it would be different if you met with a really negative reaction or people that say 'oh, poor you', if it made you feel sorry for yourself...

Rebecca, Natasha, Maxine and Daphne do not have, it would appear, an internalised 'personal tragedy' response which has been supported, I would suggest, by access to alternative discourses and the use of resistance and strategies to counterbalance experiences of oppression.

In terms of strategies and resistance used by the women and their politics of change, of note is that while Natasha had the highest number of experiences of powerlessness and constraints, she also has the highest total of strategies used, which could have prevented her from succumbing to her experience of oppression. Also of note is that the two participants who are least affected by disempowerment and social constraints have no references to a politics of change - it is possible they have no need for such a stance.

CONCLUSION

This chapter has presented and further developed the theoretical discussions of the social model of disability. Such a model is politically motivated to agitate for change at all levels of society to expose and challenge oppressive discourses, practices and policies which undermine the civil rights of disabled people.

The responses of the participants in this study were presented in terms of their experiences of powerlessness or worthlessness at three levels of society, along with their experiences of empowerment or being valued. As discussed, there are a broad range of experiences within the data which could suggest that

certain outcomes for these women might be predicted - that a high level of powerlessness and a low level of empowerment could result in increased experiences of social oppression.

The data did expose a number of policy issues which impact negatively on this group, and which, using the theory of social oppression, are identified as disabling to these women. These issues included lack of access to adequate treatment, equitable employment opportunities, the physical environment and economic security.

The use of this theory to expose these issues indicates that it is possible to tease out the differences between the impacts of the disease on this group of women and the impacts of socially oppressive practices and policies. In so doing, the application of this theory begins to address the research question as to whether the discourse of medicalisation... impacts on the participants more than that of their disease.

For at least two of the women (Maxine and Natasha), the impact of oppressive practices is (or has been in the past) more significant to them than their impairment, particularly around employment issues.

For four of the women (Kate, Josetta, Marie and Debbie), there is a need to first address the impact of their disease appropriately through adequate treatment or home alterations before such a statement could be made. For Marie and Debbie, medical treatment and social theory could combine to struggle for better management of the disease **and** the policy that oppresses them. Should their disease be well managed medically, then better identification of the impact of oppressive practices could probably occur.

Joseffa's economic problems and lack of support to achieve her goals add to her significant 'hidden' impairments. While addressing the social issues won't change her impairments, they may enable her to reassess her position of powerlessness. Kate's, disease also impacts significantly on her, but her definitions of 'independence' have altered with the disease, and in obtaining appropriate conditions within her daily lived experience could mean the impact of the disease becomes less to her than before.

Two of the participants (Rebecca and Daphne) reported very few experiences of powerlessness or oppression; Daphne has experienced the positive effects of policies which supported and met her needs adequately. This has left her in the position of not only having **choices** in her retirement years, but **multiple choices** which have resulted in her remaining very involved at all three levels of society. It is interesting to note that as the participant who has gained the most from policies supportive of impaired people, Daphne rejects the social oppression theory.

What the social model of disability doesn't examine, as previously discussed, is the bodily experience of disability, particularly the impact of a chronic degenerative disease such as Multiple Sclerosis. While I have debated that it is possible to separate out the effects of the disease from the oppressive practices of society, the reality of the disease is that from day to day, the impact of Multiple Sclerosis may take precedence regardless of the absence of oppression; or alternatively, may combine with the effects of oppression to create a particularly vulnerable subject position within society. Kate and Joseffa's positions may well be such a combination.

The issue of the lived experiences of these women in terms of their disease process will be examined in the next chapter, along with a second alternative discourse - that of Feminist theory and disability.

CHAPTER SEVEN: OPPRESSION? FEMINISM, DISABILITY AND MULTIPLE SCLEROSIS

INTRODUCTION

Within the previous chapter the first research question of this study began to be addressed. That is, an analysis of the participants' narratives exposed some of the ways in which the medicalisation of disability resulted in oppressive experiences for most of the participants. But this study also examines the ways in which patriarchal discourses may impact on women with Multiple Sclerosis. The review of literature in Chapter Two introduced some of the debates raised by a feminist analysis of disability.

This chapter further develops these debates, beginning with the lived experience of having a degenerative disease. Issues of invisibility and invisible symptoms are compared with the issue of hiding impairment, along with the concepts of 'time', 'work' and 'productivity'.

The dependence-independence dichotomy as a patriarchal concept is further discussed from a disabled feminist perspective. This leads to a discussion on the development of a politics of difference in which the multiple subject positions of women can be recognised and celebrated.

Following this discussion, the experiences of the women in this study are presented in terms of their relationship to the theoretical debates, and this chapter concludes with an analysis of how feminist thought can contribute to politicising the experiences of women with Multiple Sclerosis.

THE LIVED REALITIES OF IMPAIRMENT

In examining the bodily experience of impairment, disabled feminist thought seeks to recognise and acknowledge the struggles and strategies involved in living with the realities of impairment that 'would persist regardless of the society in which we live' (Morris, 1991:71). In so doing, the effects of disablement as outlined by the social model of disability are able to be identified, **without** denying the physical reality of lived impairment.

Such an approach also acknowledges the significance of chronic degenerative diseases like Multiple Sclerosis, recognising that the disease, in most cases, will result in increasing impairment over a lifespan. As Lonsdale suggests:

Disability is not a matter of choice... The impact it has on the life of an individual often results as much from the physical progression of the disability as the way in which that person is defined and treated by the society in which he or she lives (1990:142).

In acknowledging such a disease process, disabled feminist approaches also allow for a recognition of the very real emotions and feelings which such experiences raise. Multiple Sclerosis can be a very frightening disease - we may deconstruct **disability** to clinically assess societal reactions and constraints as oppression, but that does not remove the very personal emotions felt by those living with the disease as they contemplate a future in which increasing impairment is likely.

A feminist approach can enable us to name these emotions as valid and important while maintaining the focus that personal experience is linked to political or public issues. In so doing, feminist theory can acknowledge fear for example, while at the same time addressing whether the fear is caused by the

risk of further impairment, or by the thought that should such impairment occur, there would be a lack of adequate support to manage.

FEMINIST DISCOURSE AND DISABILITY

Invisibility and hiding disability

Lonsdale (1990) argues that very little attention has been focused upon disabled women - and it could be debated that this continues today. She asserts that as a result, women are rendered 'all but invisible' (1990:42) within the literature on disability. She asserts:

Women with disability are rendered invisible in a host of different ways. First they actually appear less, and are literally, seen less often in public. Second, even when they are not physically out of sight, they are psychologically out of sight. Third, as a minority group, they are often ignored and devalued by the majority (1990:42).

Jenny Morris agrees, and develops this further in so far as the general culture (media, arts, writing for example):

...invalidates me by ignoring me and by its particular representation of disability (1991:85),

and argues that by being misrepresented within our culture, disabled people as well as non-disabled have:

few points of reference with which to make sense of our reality (Ibid:85), adding: If our reality is not reflected in the general culture, how can we assert our rights? (Ibid:91).

In attempting to avoid the invisibility of oppression, many disabled women may go to great lengths to hide their impairment instead, in order to 'pass' (Morris, 1991, Hillyer, 1993) as non-impaired. Hillyer discusses at length the reasons for and benefits of passing, arguing that:

As long as the penalties for being an open member of a minority group are severe, many individuals who can pass will do so (1993:150).

Hillyer also debates the physical and psychological costs of hiding impairment, which, if taken to extremes can result in further impairment due to a denial that one is ill. Morris debates the lack of visible role models for disabled women, asserting that another way of 'passing' (1991:36) is to present oneself as an exception to the disabled 'rule' - the 'I might be disabled, but I lead a normal life' (1991:37). Adrienne Rich (1983) argues that such 'exceptions' divide disabled women from the group to which they belong, and asserts that in so doing:

...make invisible my oppression. That division can compound my isolation, as well as make me politically impotent (1983:56).

The reasons for hiding impairment are many, and while Hillyer argues that doing so maintains the repressive system that creates it (1993:50), she also contends that each woman who hides disability has her own reasons for doing so which need to be respected.

An issue for many people with MS is one in which the impairment itself is 'hidden' or 'invisible'. That is, it is not noticeable to others, and therefore may not be recognised. Examples include fatigue, bladder problems, pain or vision difficulties. Where such invisible impairments are coupled with strategies to 'pass', one may be accepted as 'normal' in society - but at a cost at times.

Where such impairments exist and the person with MS is explicit about them, the response of others can be frustrating, as they may fail to see the effort that is required to manage them. This can result in pressure from able-bodied

society to continue to pass regardless, particularly within the workplace and home, as they appear 'normal'. To not pass can bring about sanctions and recrimination.

Time, Work and Productivity

Hillyer (1993) asserts that the concept of time and the value placed upon productivity within our society is one of the ways patriarchal cultural values are transmitted (1993:47). She argues that 'external clock time' (Ibid:58) emphasised by our (western capitalist) culture makes it difficult for disabled people to continue to participate within the working environment. Lewis & Weigert addressed this in their earlier work, arguing that organisational time takes precedence over self time, and that strong social sanctions maintain this precedence (1981:444 - 445).

Impairment and illness, particularly a chronic, degenerative disease such as Multiple Sclerosis frequently disrupt 'clock time', in that the disease is unpredictable and erratic, it may take longer for a person with MS to complete tasks or they require more frequent rest breaks. Such a change in 'pace' (Hillyer, 1993:68) is frequently viewed as also resulting in decreased productivity (Georgeson, 1994).

Multiple Sclerosis often requires the use of flexible or reduced working hours. Davoud & Kettle's (1980) study of 1243 people with MS revealed that employers would generally accept a reduction of one or two hours per day in working time, but more than this would result in the employer beginning to propose early retirement (1980:60). Lonsdale argues that in such a system:

A person is judged as either capable or incapable of full time work. This system forces many men and women to become dependent on the state when they wish to work. It ... embodies a

view that people are either totally disabled or totally able-bodied. The reality, however, is that people are rarely 'fit' or 'unfit' but fall on a continuum... (1990:107 - 108).

The concept of time is not only confined within the environment of paid employment. Similar debates around time, work and productivity may be applied within the 'invisible' workplace of the home, where changes in roles or pace of work may be viewed as reflecting a reduction in productivity within this sphere. Women at home may be loathe to ask for help from their partner, particularly if he or she is in paid employment.

Alternatively, if receiving help at home, much of disabled womens' time may be organised around the arrival of helpers, personal caregivers or nursing staff which may involve lengthy periods of time spent 'waiting'. Such waiting may decrease productivity by attrition - time used waiting could be utilised in other ways. Waiting also frequently occurs at medical clinics - what Doris Lund (1974) refers to as 'an illness all its own'.

The physical demands of a degenerative disease such as MS may require that a person re-evaluate the ways in which they spend their time, by setting priorities and pace-setting (Ottenberg,1978), as well as learning to rest, which is often prescribed for Multiple Sclerosis. Such strategies are often considered deviant within the workplace and employers are frequently resistant to adapting working conditions to allow for flexible arrangements. Morris argues that as a result:

...people who are unable to engage in paid work are made dependent - on someone else's pay, on state benefits or services, or on charity... [which] has certain social, political and personal implications and can create unequal power relationships (1991:140).

Such dependence, generally defined by non disabled people, and underpinned by economic and medical model discourse creates and sustains what is frequently referred to as the dependence-independence dichotomy.

The Dependence-Independence Dichotomy

A feminist analysis of the concept of 'dependence' has generally focused upon womens' economic dependence upon men as a negative construct underpinned by patriarchal discourse. As a consequence of such dependence, womens' oppression is located within the patriarchal family system and can result in experiences of subordination and helplessness. Feminist theories seek to address such issues by challenging the structures and practices which support such positions of dependency.

However, when applied to the situation of disabled women, most feminist writers assume that dependency is due solely to their physical limitations (Morris, 1991). Also of note is that 'independence' as defined by non disabled people, means:

...both physical and emotional autonomy, and the focus is on the individual's ability to achieve this autonomy. When individuals cannot carry out the tasks of daily living for themselves, this is associated with dependence... and independence is assumed to be impossible (Morris, 1991:139).

Disabled writers and their non-disabled allies argue however for a redefinition of the concept of 'independence' (Brisenden, 1989; Lonsdale, 1991; Hillyer, 1993), as well as for the recognition of a continuum of dependence and independence, or interdependence rather than an artificial dichotomy between the two concepts (Hillyer, 1993; Georgeson, 1993, 1994).

Issues frequently associated with this dichotomy are those around receiving 'help' or 'care'. Over the past ten years, the issue of 'care' has been discussed

from a variety of perspectives, from the invisible and under-resourced work of caregiving (Lloyd, 1992; Munford, 1992, 1994b; Hillyer, 1993), to vulnerability and abuse within caregiving relationships (Sobsey, 1992); the experience of 'help' or 'care' which is oppressive or demeaning (Lonsdale, 1990, Morris 1991); or the use of one's need for care to exclude from rather than promote inclusion in society (Georgeson, 1993).

When society as a whole fails to recognise that, as inherently social beings, humans require various levels of support regardless of impairment (Bunkle and Lynch, 1992), the dependence-independence dichotomy remains. Any 'difference' in terms of impairment and needs for assistance therefore becomes a negative construct which further confirms 'dependence' as an undesirable state in which 'unproductive' people are cast.

Such assumptions about dependence, along with those pertaining to the concepts of work and productivity are being challenged by disabled feminists. Drawing upon the social model of disability and feminism, such a challenge promotes the development of a 'politics of difference' in which differences are valued and celebrated.

EMPOWERMENT AND RESISTANCE: A POLITICS OF DIFFERENCE

Difference and Similarity

The 'difference' of impairment is profoundly disturbing to Western societal values of normalcy, homogeneity and conformity. Utilising the tools of power and discourses of medicalisation and patriarchy, mainstream society negatively defines, describes and categorises disabled people as 'other'. Such difference is then 'repressed by structure' (Haber, 1994) in that societal, environmental and political structures maintain "other" as a negative construct. Barton (1993) argues that when 'otherness' is portrayed negatively, finding one's identity

becomes problematic and disabled people as 'other' remain invisible, unheard and marginalised as a consequence.

The challenge then is to develop an 'oppositional politics' (Haber, 1994) which reconceptualises the construct of 'other' into the recognition and valuing of difference. In doing so, such a politics offers a means by which to move from positions of marginalisation, invisibility and silence (Barton, 1993; Munford, 1994a) to developing an identity and language (Morris, 1991; Munford, 1992; Hillyer, 1993; Haber, 1994) with which to name our experiences of impairment and oppression.

In establishing a disabled identity which names our worlds and experiences on our terms, and is supported by a disability culture (Morris, 1991), both difference **and** the similarities we share can be acknowledged and celebrated. Similarities and differences between disabled men and women can be drawn (Lonsdale, 1990; Wicks, 1996), as well as between women. A disabled identity will thus reflect multiple positions within the disabled community which can be drawn together as a political force.

Multiple Subject Positions

Many non-disabled people make the assumption that a person's impairment is the most dominant and important part of their identity (Lonsdale, 1990). For some women, positions of dependence result in **disability** becoming the 'central organising feature of their lives' (Munford, 1995), but for many, **impairment** is but one aspect of lives in which multiple experiences (Kondo, 1990), aspects (Munford, 1995) and multiple 'identities' (Sawicki, 1991) co-exist within a diverse and rich intertwining of social environments, experiences and contexts.

This is a particularly useful means by which to develop an understanding of how women with Multiple Sclerosis may shift and change subject positions in response to their experiences with the disease. One day may see the management of MS taking precedence, another may focus on the struggle to obtain employment within a patriarchal capitalist setting, while the disease is given less of a priority. One week the 'identity' of a woman with Multiple Sclerosis appears no different to those of her 'mainstream' community - the following week she may be encased within the medical system being treated for an acute exacerbation and facing further impairment. In these experiences lie our similarities **and** our differences. Within these experiences lie the foundations of a politics of difference.

A Politics of Difference

As discussed within Chapter Two, a politics of difference begins with self respect and self knowledge (Haber, 1994:124). Once such a goal has been reached, it becomes possible for a person to:

...insert her or his needs within the larger social structure, disrupting the complacency of the existing social and political "we" (Haber, 1994:124)... to make sure differences are spoken and battled continually (Ibid:125).

Haber goes on to argue that recognising 'points of similarity' (1994:132) is the key to an oppositional politics, which:

allows me to deny the idiosyncratic nature of my experience, to deny my guilt at being different from the 'norm'. The recognition of similarity and the possibility of solidarity wakes us from the stupefaction of normalising and disciplinary discourse (1994:132 - 133).

A politics of difference embodies the feminist principles of naming one's experiences and oppression, of recognising and celebrating difference and

similarity. It also develops an analysis that the personal is political. In such an analysis, opportunities for emancipation lie; so do options for a politics of resistance and action as discussed within the Literature Review.

FEMINIST THEORY OF DISABILITY AND THE EXPERIENCE OF MULTIPLE SCLEROSIS

The clinical aspects of the participants' experiences of MS were discussed in Chapter Four. But there is more to the experience of the disease than symptomology. The meaning attached to those experiences is also crucial to understanding what impact Multiple Sclerosis has had on the lives of the women in this study.

FEMINIST THEORY AND MULTIPLE SCLEROSIS

Data Results

The feminist analysis of the experience of Multiple Sclerosis for the participants focuses on the corporeal or bodily experience of this disease and impairment. This focus revisits and elaborates on the clinical data presented in Chapter Four, but from a different perspective: rather than the 'clinical' or medicalised picture of a disease process, this approach presents the lived realities of the participants in terms of their storying or narratives of daily life with an unpredictable, chronic, degenerative disease. In total, 89 references to the impact of the disease on them were made by the participants. These ranged from descriptions of symptoms experienced of the disease such as:

I lost sensation up to my waist (Rebecca)

I can't retain any information (Josetta)

I can't feel my feet (Marie)

- to descriptions of the impact of the disease on the women:

I cut my finger [off] in the food processor and I didn't feel it (Maxine)

Due to double vision, I was grounded from flying [as a pilot] (Natasha)

Also included were the strategies used by the women to manage their disease on a daily basis. An example of this would include:

I do a lot of personal pacing that no-one knows about (Marie)

I tend to live day to day... [if] I planned to go to the dentist or something, I'd three days rest so I could get [there] (Kate)

Within these narratives, a number of concepts raised in the review of the literature are discussed in greater detail as to their relationship to the experiences of this group of women. These concepts begin with the experience of invisibility (or of not being heard) and, parallel to this, the participants' reports of hiding disability. The experiences of this group of women in terms of their subject positions as women and as impaired women were remarkably complex. As is discussed in Chapter Four, four of the women have 'invisible' disabilities, yet two of these women manage severe symptoms of fatigue, pain and/or depression.

Therefore, in coding this data, a number of areas of some of the women's experiences of invisibility and of hiding impairment raised dilemmas around which way to code the data. For example, if an impairment is 'invisible', is it therefore 'hidden'? For some of the women it was hidden as well. Or, alternatively, if a woman reported feeling 'invisible' due to 'hidden' impairment(s), which set of data would it be coded under? These dilemmas were managed in the following way:

- If impairment was 'invisible' due to the nature of the impairment (no one else could recognise it's presence) **and** such invisible impairment resulted in a reported experience of not being acknowledged, seen or heard, then it was coded under the experience of invisibility.
- If impairment was 'hidden' as a result of strategies used actively by participants to ensure it was not exposed to others, it was recorded as hidden.
- If an impairment was 'hidden' as defined above, but subsequently resulted in a reported experience of invisibility, I assessed as far as possible from reviewing the transcripts and listening again to the audiotaped interview (to analyse the content, tone used and emotional portrayal of the information) which of the two concepts had the most emphasis placed on it by the participant. Depending on where the emphasis lay within the data, the coding was ascribed to either of the two categories.

This final point arose on three occasions, primarily where, as a result hiding impairment, participants found themselves in positions of invisibility. While such an analytical approach is admittedly rudimentary, I believe that in drawing on my professional training within the fields of Social Work, the Mental Health arena and as a Marte Meo Therapist, which focuses specifically on minute communication patterns, I have made as accurate an assessment as I can under these circumstances.

Two of the responses were finally located within the experience of invisibility, and one within the 'hidden' disability category. This data produced the following results:

Figure 7.1: Participant references to the Experience of Invisibility / Not Being Heard and to the Experience of Hiding Impairment.

Name	Invisibility	Hiding Impairment	Total
Daphne	1	2	3
Debbie	5	5	10
Josetta	10	9	19
Kate	6	4	10
Marie	1	7	8
Maxine	3	6	9
Natasha	9	7	16
Rebecca	0	0	0
Total	35	40	75

The data was also coded with regard to strategies of resistance to such experiences, and produced the following results:

Figure 7.2: Participant References to Strategies or Resistance to Experiences of Invisibility and Hiding Impairment.

Name	Invisibility	Hiding Impairment	Total
Daphne	3	0	3
Debbie	1	0	1
Josetta	5	2	7
Kate	1	1	2
Marie	0	1	1
Maxine	1	5	6
Natasha	3	3	6
Rebecca	0	2	2
Total	14	14	28

Also examined within the feminist critique were issues of 'time', 'work' and 'productivity', which for six of the participants resulted in or contributed to the experiences of invisibility or put pressure on them to develop strategies to cover up for their impairment. Each of these concepts related directly to one another, as is discussed later in this chapter, therefore references to any of the three concepts were coded together. Participant responses were coded in terms of direct references, positive and negative, to any of these three concepts, and the data obtained is outlined below:

Figure 7.3: Participant References to Positive and Negative Experiences Relating to the Concepts of Time, Work and Productivity.

Name	Positive Experiences	Negative Experiences	Total
Daphne	2	1	3
Debbie	2	3	5
Josetta	1	3	4
Kate	2	7	9
Marie	3	4	7
Maxine	3	8	11
Natasha	7	9	16
Rebecca	3	0	3
Total	23	35	58

The concept of care giving and receiving has been discussed within Chapter Two as a 'dependence-independence dichotomy' - that is, an artificial separation of 'dependence' and 'independence' as mutually exclusive. A feminist analysis of such a dichotomy argues that it fails to recognise the interrelatedness of human beings and constructs disabled people as 'dependant' in a negative way.

The dependence-independence dichotomy was not only experienced by those in receipt of 'care' among the women in this study. All of the women discussed issues in which they expressed a positive or negative attitude towards becoming dependant or losing independence as is shown below:

Figure 7.4: Participant References, Positive and Negative, Relating to the Dependence - Independence Dichotomy.

Name	Positive References	Negative References	Total
Daphne	4	4	8
Debbie	6	12	18
Josetta	13	19	32
Kate	6	17	23
Marie	6	10	16
Maxine	3	3	6
Natasha	5	11	16
Rebecca	4	1	5
Total	47	77	124

Such references were made regarding a perceived or anticipated loss of independence, whether that was within family or community settings; and included issues around asking for or receiving help (all the participants); receiving care or home assistance (four participants), which included safety issues regarding such help (three participants). Positive references included the benefits of receiving home assistance (two participants), and taking some control over how care or help was to be delivered (three of the women).

As discussed within Chapter Two, a Feminist Analysis of disability argues for a 'Politics of Difference', in which the multiple subject positions of women and the differences between disabled women are validated, respected and celebrated. While the theory behind such an approach argues that a politics of difference is one in which one's impairment is celebrated as a positive aspect of a person, I will suggest later in this chapter that the development of such a politics is a gradual process and that the women in this study were at various positions in this process.

DISCUSSION

The lived realities of Multiple Sclerosis

The bodily experience of Multiple Sclerosis resulted in a range of daily struggles and the development of multiple strategies to manage the symptoms of the disease. Such strategies have been outlined in Chapter Four, and allowed most of the women to manage their disease on a day to day basis - for six of the women, such strategies developed into a routine, enabled them to continue to work (full or part time), study, socialise and/or remain involved in the community. For the remaining two, multiple strategies enabled them to maintain their current lifestyle, although they identified that additional assistance could enable them to participate more.

Some of the women discussed areas of their lives in which the impact of MS had significantly changed what they could do. Joesetta had been studying psychology and was training to be a counsellor. Due to her severe memory problems she struggled with her studies. Due to symptoms of emotional lability she found that she would laugh inappropriately during counselling sessions. In recognition that this was potentially damaging to clients, Joesetta made a tough ethical decision to stop this work.

Natasha had been learning to fly and was studying for her pilot's licence. The advent of double vision grounded her from flying and as her vision has not improved adequately, this activity remains one she can not do. Rebecca had to resign from her full time work shortly after diagnosis due to extreme fatigue. After a two year break, she resumed part time work.

Marie experienced her first severe exacerbation of MS six weeks after the birth of her baby. She was suddenly unable to care for her infant, and had to stop breastfeeding as she began high dose steroid treatment. Marie describes:

...to be in that situation, where you have got a newborn child, who has a right to a mother... I had to let the nurses take care of her and although I had her with me I just really resented that, and I resent MS for that.

Marie's difficulties with neuralgia and fatigue still impacts on what she can do with her child, as she can't walk distances. Kate and Joesetta have both given up driving, due to co-ordination and cognitive impairments respectively.

Daphne made adjustments to her life when she discovered herself 'crying with fatigue' while trying to do the vacuuming one day. She recognised that if she was going to work full time, she would need assistance within her home. Such assistance helped her to continue her working life.

Debbie, while having been diagnosed with MS eighteen years ago, had very few symptoms and no additional impairment until five years ago. As her disease is now beginning to progress, she is struggling with changing roles and increasing impairment.

Invisibility and Hiding Disability

For many of the symptoms of Multiple Sclerosis, management becomes a daily routine, often invisible to outsiders. But 'invisibility' as discussed earlier in this chapter, has also been experienced by all except one of the women in this study. In Lonsdale's terms of appearing less, two of the women are infrequently out in their wider community. However, for Kate, while access out of her home is an issue, so too is the impact of fatigue in that trips are profoundly exhausting.

Four of the women have 'invisible' impairments. But the impact of fatigue, pain, depression or cognitive impairment has at times led to people not seeing, or ignoring their needs for support or assistance. Each of these women has also experienced times when impairment has been obvious - for some of them this created a different sense of invisibility. For Josetta, being on crutches was:

...really hard, it was like I became invisible... people see you, but they don't see you... they don't see you as a person, they see you as disabled.

- and yet, appearing 'normal' comes at a cost. When using crutches and needing to sit down on the bus, people would offer Josetta a seat, but:

you get rid of those sticks, I don't look disabled any more, but I still have trouble standing and things like that, but people don't care - you look OK.

All of the participants except for one have at times hidden, or felt they needed to hide their impairments. These have ranged from temporary strategies to manage an oppressive situation or to 'prove' oneself capable (two participants), to making a deliberate, carefully considered decision not to tell others of having the disease (one participant).

Four of the participants have more obvious impairment which makes hiding not an option, but this has not prevented them from at times minimising symptoms in order to avoid closer scrutiny. One participant has never experienced a sense of being invisible or not being heard, and has the attitude that covering up MS does not do any favours for oneself or for the disease. Hiding impairment is however one facet of 'passing' in the non-disabled world, another is to push or 'prove' oneself as capable, particularly within the work arena.

Time, Work and Productivity

All of the participants made references to the concept of 'time' within this study. Three of the participants took 'time out' - for rehabilitation (one), to spend more time with family (one) or to re-evaluate and give time to herself (one). One participant, having retired, was enjoying using her time to be involved in a variety of leisure and family pursuits.

One participant introduced the concept of time as regulatory in terms of receiving care, and four participants referred to time spent 'waiting' - for clinics, for a diagnosis, for treatment, care or assistance or for equipment. Kate in particular critiqued how much time was lost through waiting - her descriptions of waiting, including having to wait six months for a wheelchair exposed how the incoordination of the public health system exacerbated the difficulties she was experiencing due to her impairments. Waiting time also related to the disease

itself - waiting for symptoms to go away or waiting to recover from an exacerbation for example.

Most of the women in this study alluded to making use of time management strategies to manage their work at home or work place to reduce fatigue, or to work more effectively within the boundaries of their impairments and the disease. Such strategies made use of 'pacing' oneself to get through a day, prioritising activities , or resting before an outing.

Many of the work issues faced by participants have been discussed in the previous two chapters. In addition to those issues are issues of productivity and pace. Negative experiences included being monitored within the workplace regarding outputs, productivity and use of time, to believing that using strategies to manage MS at work meant two participants were somehow less 'productive' than their colleagues.

*I just know I don't do as good a job at [n...]...I don't like to take money for work unless I do a good job, I **really** do a good job. I think if you ask other people, they'd say I was being way too hard on myself, - but that's what I think (Marie).*

Or, as Debbie describes, despite meeting her required work targets:

...I feel like I'm not pulling my weight.

While Natasha, having arranged flexible working conditions including being able to 'bank' time in her new job was more confident:

...my flexible arrangements have meant that I have been able to meet all the required outputs and carry an equivalent load to my peers - just in a different way!

Three participants commented they did not feel able to ask for assistance at work or within the community due to the perception one was less productive as a result, or was wasting another's time. Three other participants had no concerns about asking for help in this way.

Positive references to these concepts were made at a ratio of 1 to 1.5 negative responses. These included being treated as productive within the home, workplace or community, and being expected to manage time to fit in with the demands of the disease rather than an organisation, working flexible time and taking time to rest in the work setting. Other positive references included others adjusting their use of time to offer support and assistance (four participants). Finally, the positive use of strategies to 'pace' oneself within the work and home environment was referred to by four participants.

In terms of productivity within the home, two of the participants expressed a reluctance at times to ask for assistance, although for different reasons. Maxine was in charge of the running of the home, and felt it was unfair to ask her husband for help as he worked full time, while Josetta struggled with the housework, and didn't often ask for help from her husband because she didn't want to 'hack him off'. Marie's husband, as discussed in Chapter Six, could not support her in terms of his cultural understanding of illness, but at a practical level within their business and in the home, 'he was just a huge huge support'.

Rebecca and her partner share roles within the home and her partner encourages her to let him take on additional jobs when she is tired. The two years Rebecca took time out after being diagnosed allowed her to re-evaluate her roles within the family, her work and leisure pursuits, which led to a shift in focus where she now spends more of her leisure time with her family, a positive change for her in response to the disease.

Debbie however had a different approach - when she recognised her condition was deteriorating, she 'trained up' her husband to take on additional roles which he now does for her when she is struggling. For Debbie, still being able to occasionally manage some of the heavier tasks around the home is a source of pride for her as otherwise she felt as if she were losing her independence.

The Dependence-Independence dichotomy

The continuum of dependence and independence proposed by writers such as Hillyer and Georgeson applies well to the eight women in this study. Each participant to some degree currently required, or had required assistance, and, due to the nature of the disease, most likely would require assistance in the future. For each participant, receiving help or care raised a mixture of responses and held different meanings for them.

Daphne and Natasha both receive paid assistance which enables them to maintain active lifestyles and remain included in their communities (both) and workplace (Natasha). Both these participants had input into who they would receive help from, with Natasha selecting her own caregivers, and Daphne screening out home helpers she was not comfortable with. Kate receives both home help and personal cares, but this is not flexible, meaning that Kate must arrange her day around the arrival of caregivers:

I'll have my breakfast now, then of course I have people who come and help me... so that's a regul... I can't say regulatory - it is , so you have to sort of prepare yourself for them to come.

Given that it is Kate who is receiving care, she has few **choices** around when she will receive care, or by whom. This has raised a number of safety issues for her - her personal caregivers, who are required to lift, bathe and assist her with dressing, frequently have had no training in safe lifting practices which Kate

finds very 'risky'. Additionally, given that she has two autoimmune diseases, she frequently has to educate caregivers on basic hygiene, including not coming to work with her when they are ill.

Both Kate and Natasha expressed concerns at the poor rates of pay that caregivers receive, which discourages qualified people taking on such roles. As a consequence, many of the caregivers Kate has had experience with, are women who themselves come from positions of oppression:

...a lot of the people who come and help me, they had dreadful problems, terrible problems you know, not just husbands going and leaving them with children, but abusive husbands... you listen to people's problems - in a sense worse emotional problems than I had... It can be tiring (Kate).

Rebecca is considering privately employing home assistance in the future to help reduce fatigue and increase her options for other activities. She does not perceive this as a loss of independence however. Positive references to the issues of care or help related to the impact of friendships or family who shared or assisted as a 'fact of life' rather than in a formal way. Daphne sums up her situation:

I have so many special people in my life...a lot of my friends come into my house and they just take over my kitchen and that sort of thing and I let them. Nobody ever puts me to any increased effort... we don't even talk about it. It just happens.

Daphne also offers a positive insight into the way in which the reciprocal nature of such relationships fits within a continuum of dependence:

...it's an interactive thing, you have to be a friend as well ...

Maxine, Natasha and Rebecca also commented positively on the ways friends and family helped. Josetta had ambivalent responses to help, from discussing

the positive assistance of a close friend, to an uneasy resentment when strangers offered help, perhaps reflecting a recognition of what Morris (1991) terms the 'pity mixed with distaste' attitude. Josetta preferred being able to identify when she needed help herself, rather than have people make assumptions about her needs.

Debbie struggled with asking for help at work, due to a combination of negative responses from two colleagues, internalised discourse that she was not pulling her weight and ambivalence about her own increasing impairment. Debbie recognises that her first steps in addressing these issues involve her own ambivalence:

One good thing to put in place would be me accepting it more, not worrying about having an attack... and not worrying about what people said to me - just accepting it myself.

Debbie, it appears, is beginning to debate her internalised discourse that difference is a negative construct. In terms of a politics of difference, she is taking first, tentative steps to validating her own different existence.

EMPOWERMENT AND RESISTANCE: A POLITICS OF DIFFERENCE

Difference, Similarity and a Politics of Difference

Multiple Sclerosis, as discussed, is a highly individualised disease. The experiences of the women in this study are therefore also highly varied. Yet, within their experiences lie many similarities as well. Daphne and Rebecca, despite an age difference of thirty-one years, share similar experiences of little physical impairment, a relatively quiet disease process (Daphne) or a quietening one (Rebecca). They also have support from friends and/or family to resist internalising a 'personal tragedy' discourse. While Daphne has now retired, she continued to work, as does Rebecca. Both Daphne and Rebecca

hold positive attitudes towards themselves and to receiving assistance, and do not view help as a loss of independence.

Both women have been able to access state assistance to improve the quality of their lives - Daphne for transport and home help, Rebecca for treatment. Both women have strong opinions which they are not afraid to make known. Daphne is experiencing more similarities than differences to her peers now as they age; Rebecca also has few visible impairments to make her noticeably 'different' from her peers. Both women made no references to a politics of difference, although both value themselves as 'different'. As it was for the social model of disability, it may be that neither has had the need to develop such a politics.

Maxine, Debbie and Marie have different impairments. While Maxine is very open about having MS, and resists an internalised medical discourse, Debbie reports hiding her limp by not walking in front of people to avoid embarrassment. It does not appear that Debbie has had access to an alternative discourse around disability.

While Marie does have access to her sister's alternative discourse with regards to having MS, she has made a conscious decision to not expose herself to others' scrutiny by not informing them she also has the disease. She recognises that at times this is problematic, and it is not a strategy she plans to use long term; but perceives that the costs experienced in the past when she has identified herself as 'different' have far outweighed any benefits.

Additionally, Marie anticipates that within the job market, such an identification would not be to her advantage. Maxine's experiences would tend to support this, as would Debbie's current work situation. In terms of receiving help, none

of these women felt prepared to ask an employer for assistance. While all had received help in the past from a variety of levels, the responses of two of this group reflected a negative perception overall in terms of this reflecting a loss of independence.

All three of these women made just one reference within the interview which reflected a politics of difference: for Debbie, it centred around her acceptance of impairment, Maxine's related to acknowledgement of her 'plastic leg', while Marie referred to the difference between herself and her sister in their approaches:

[sister] told everyone - that's because she's the most pretty honest... very open person...her and I are total opposites in this point of view, but I totally accept what she's got to do for herself as she does for me.

Given the low responses of these participants in terms of a politics of difference, I would suggest that in the presence of any of the following:

- internalised discourse (whether this be medicalised or patriarchal in nature)
- increasing levels of oppression gradually undermining one's own positive discourse
- an absence of or lack of access to an alternative discourse (whether this be those under discussion or others);

then the development of a politics of difference may be at best, difficult, or even impossible, as most of a person's time becomes taken up with the daily struggles of living impairment within societal structures that are not supportive of such (or any other) politics. I suggest that it takes time to be able to develop a politics of difference - time to access an alternative discourse, to reflect on

what it might mean in light of one's own experiences and time to adapt such a politics to one's own lifestyle.

The final three women in this study have begun to develop such a politics. Natasha, Josetta and Kate have all experienced high levels of impairment, resulting in significant lifestyle changes. All three participants receive (or have received) home help or care; for Kate and Natasha this maintains their current levels of independence. For Kate however, receiving paid care only during the week means her daughter must travel to assist her each weekend. Kate would prefer to be:

Totally independent so that my children don't have to come up.

'Totally independent' to Kate does not mean a return to previous abilities - and she critiques the medical and welfare systems in terms of their lack of recognition of her difference and, as a consequence, the lack of adequate provisions to enable her to live independently - on her terms. Josetta has a similar critique to Kate which has previously been discussed.

While each of these women have developed an awareness of difference, and attached to this awareness a recognition of their rights to be treated as citizens within their society, none has taken the further step of identifying difference as something to be celebrated. Again this may reflect the presence of the previously mentioned constraints, or alternatively that the impact of the disease gives little to celebrate. It may also suggest that these three women are simply at a certain point in the development of such a politics.

Multiple Subject Positions

All of the above discussions reflect some of the multiple subject positions held by the women in this study. As mothers, wives/partners; workers, welfare

recipients, volunteers, retirees; caregivers and care receivers these women have a multitude of roles. As women, women with MS, impaired and/or disabled women, ill, well, fit or fatigued, wealthy or poor, courageous, fearful, humorous, angry, sad, joyful, struggling or strong - these women have a multitude of experiences.

Furthermore, throughout their lifespans, the participants have been many of the above. Each member of this group has at different times, in different contexts, described each of these multiple subject positions within their narratives. At any given time, depending on their situation or circumstances, one or several of these positions were present as part of a complex persona. Within each woman's narrative lay descriptions of their ever-changing subject positions; changes that occurred because of their disease, but more frequently because of the multiplicity of roles they played within their families, homes, workplaces, communities and society at large. Each of the women in this group, while in so many ways different, were, in just as many, also similar.

Men and Women with Multiple Sclerosis: A Politics of Difference?

Each of the women in this study was asked whether or not they believed the experience of MS was different for men and women. One of the participants did not know. The remaining participants gave 16 responses that men and women with MS did experience the disease differently, and 3 responses that they did not. In terms of the disease process, two women felt that men had more progressive forms of the disease, while two felt it was no different - one participant amended this to exclude pregnancy and following birth as causing some difference for women.

Two participants felt that in terms of men's roles as 'providers' within the family it may be more difficult for men to cope with job loss, while one participant felt that men would be encouraged more to remain in work. Another felt that men

and women were equally 'driven' in the workplace today and that they shared similar goals. This participant also felt that men and women shared the same feelings, worries and doubts about the disease.

Three participants believed that men with MS had more difficulties within their relationships, and one believed that issues around sexuality would be particularly concerning for men. One participant pointed out that following diagnosis, women were still required to take on the role of 'mum' even if not in paid employment, and one suggested that as most doctors were male, perhaps men received better or quicker treatment. Finally, one participant felt that men were socialised differently around illness and impairment.

While a thorough exploration of these issues is beyond the scope of this thesis, this group of women did identify differences and similarities between their experience of MS and those of men they knew. These responses suggest that this is an area which could be further researched in the future.

CONCLUSION

The purpose of this chapter has been to examine the contribution of disabled feminist theory as it applies to the experiences of the women in this study. The lived experience of Multiple Sclerosis has been revisited in terms of some of the meanings attached to the participants' experiences of the disease. The concepts of invisibility and hiding impairment revealed the complexities of being 'invisible', experiencing invisible impairment and hiding impairment to survive in a market driven economy.

The participants' experiences around issues of time, work and productivity revealed both positive and negative occurrences, as well as discussed some of

the positive strategies used by participants regarding time usage and management of their disease.

The dependence-independence dichotomy was explored, and the suggestion of a continuum of dependence was reflected within the data. Issues raised by the data included a lack of choice in receiving care, lack of trained and poorly paid caregivers and safety issues as a consequence. The positive aspects of help were also discussed, along with some of the women's responses to receiving help.

Developing from this discussion is consideration of the development of a politics of difference within this group. I have suggested that such a politics requires time, access to such a discourse and an environment which enables women to consider and develop their own views around this approach, although overall, the participant's responses did not support such a politics.

The multiple subject positions of the participants in this study were recognised and reflected on, as were their opinions on the experiences of men and women with Multiple Sclerosis. These reflections suggest that further research to compare these experiences from a socio-political perspective may be useful to further develop social and feminist theories of disability.

Having now presented and discussed the data results separately in terms of a Foucauldian analysis, the social model of disability and from a feminist perspective, it is important to draw the threads of each together to present an overview of the data obtained. The next chapter summarises the data and takes into account the experiences of the women in this study from all three perspectives combined.

CHAPTER EIGHT: IN FROM THE MARGINS: LIVED REALITIES OF DISABILITY

INTRODUCTION

Drawing from the data presented throughout the previous four chapters, the purpose of this chapter is to summarise and present an overview of the results obtained within this research. The reader is briefly reintroduced to the participants, following which each of the key concepts and theoretical constructs employed within this study are summarised from Chapters Five to Seven. Finally, this chapter combines the total responses of the participants to give an overall evaluation of the experiences of the participants in this study.

THE PARTICIPANTS

The eight participants in this study represented a broad range of ages, abilities and experiences which allowed for a wide variety of responses to be gathered to represent 'above average, average and below average cases' (Patton, 1990). In terms of the age ranges of this group, two women were aged sixty or over, two were in the thirty to forty age group, and the remainder were aged between forty and fifty years. The cohort experiences however were varied as were the experiences of Multiple Sclerosis and the levels of impairment within this group.

The length of time since diagnosis also varied - but as discussed already, prognosis in Multiple Sclerosis is difficult. As discussed in Chapter Four, the clinical picture of the disease is not enough to truly understand what life is like with Multiple Sclerosis. Each of these women, while managing clinical aspects of their disease, also contended with numerous personal, family and societal responses to their MS and to their impairments as their disease progressed.

FOUCAULT, MEDICALISATION AND MULTIPLE SCLEROSIS

This analysis of the data examined the medical framework which all people with MS enter prior to or at the point of diagnosis. In particular, Foucault's technologies of power and discussions of the subject / object of knowledge and power were examined within the data; along with Foucault's concept of the internalised discourse of the disciplined individual.

In terms of the data obtained, overall the participants' negative experiences of Foucault's technologies of power and medicalisation outweighed their positive experiences or resistance to such technologies by a total of 178 negative responses to 121 positive. Within the group were some significant differences which have been discussed in Chapter Five; and from which arose the suggestion that further exploration of the process of internalising discourse could assist workers in identifying when someone with MS may be at risk of internalising oppressive discourses.

THE SOCIAL MODEL OF DISABILITY AND MULTIPLE SCLEROSIS

Within this theoretical model, two key concepts were examined - those of the experience of powerlessness or worthlessness, and the experience of disabling constraints defined by this model as oppression. Also examined, as a counterbalance, were participants' positive experiences of empowerment or being valued, and their experiences of enabling assistance as social emancipation. The participants' negative responses outnumbered their reported positive experiences by 205 to 135.

The experiences of powerlessness, worthlessness and those of empowerment and being valued were further analysed as to what levels of society each experience occurred within. The relationship overall between negative and positive experiences at each societal level indicated that while more positive

than negative experiences occurred within the family level of society (45 : 32), the broader community to societal levels reflected an increasing number of negative responses with fewer counterbalancing positive responses. This would indicate that the reported experiences of the participants in this study would support the assertion that societal discourses are structured in a way that is not generally supportive of women with MS, particularly in terms of working environments and welfare and adequate treatment policies.

The data was analysed in terms of strategies and resistance to oppressive experiences, as well as evidence of a politics of change. The results of this analysis revealed a variety of strategies were used by the participants in response to their experiences, and they made a variety of suggestions in terms of a politics of change. One participant, having been exposed to the social model of disability, advised that she did not agree with this theory.

Overall, an emerging trend raised the possibility of identifying a 'risk' of socially oppressive experiences and the suggestion that one could explore the possibilities of developing strategies with women at risk of experiencing disability as social oppression.

While this set of data evidenced that it is possible to separate out the impact of socially oppressive discourses and practices from the experience of impairment, the acknowledgement was made that such an analysis did not take into account some of the feminist debates of disability. The following analysis therefore was undertaken to address some of these debates.

FEMINISM, DISABILITY AND MULTIPLE SCLEROSIS

Analysis of the participants' data from a feminist perspective revisited the physical impact of Multiple Sclerosis on the women. A total of 89 references to

the impact of the disease ranged from descriptions of symptoms to changes the women had made to their lifestyles and strategies they used to manage the disease.

Within the narratives of the participants a number of concepts raised within the feminist perspective were also analysed, including the complexities of invisibility, invisible impairment and hiding impairment; and the interrelated concepts of 'time', 'work' and 'productivity', particularly within the context of a market driven economy such as our own.

In terms of the experiences of invisibility and hiding impairment, the combined totals of 75 references to invisibility and hiding impairment as opposed to 28 references to resistance for this group of women would tend to support the assertion that women will go to significant lengths to 'pass' by hiding impairment (Morris, 1990; Hillyer, 1993), although as discussed within Chapter Seven, there were variations across the group.

The concepts of 'time', 'work' and 'productivity' resulted in 23 positive and 35 negative responses from the participants. These responses related to both paid employment and the roles undertaken by the women in their home. Coupled with the experiences outlined within the community level of society in the social oppression data analysis, the significance of these results suggest that this group are particularly vulnerable to job loss and/or pressure to leave work.

Analysis of the dependence-independence dichotomy produced a total of 77 negative references compared to 47 positive. While these results have been discussed within Chapter Seven, the variations in responses from the participants supported the argument that recognition must be given to a

continuum of dependence and independence rather than the current dichotomous thinking around the two concepts.

Finally, the data was analysed in terms of the multiple subject positions of this group of women and the development of a politics of difference as debated by this perspective. The group of women in this study revealed within their narratives a multitude of subject positions, and an ability to move between positions according to the demands of an unpredictable disease and the multiple roles they have. The development of a politics of difference was not generally supported by the data, although individual women in this study revealed various positions within the process of developing such a politics.

SUMMARY

Having now presented and examined the data results in terms of each of the theoretical constructs individually, one may make a series of assumptions about the women's experiences of each within this study. But the information as it is presented at this point in time is fragmented and it is important to now draw together all the results to gain an appreciation of how the first research question has been responded to by the data.

Firstly, the total number of responses for negative experiences - those which would support the statement that patriarchal discourse and the medicalisation of disability could exclude and oppress women with Multiple Sclerosis - are presented below:

Figure 8.1: Total Number of References to Negative Experiences: Foucault & Medicalisation, The Social Oppression Model and Feminist Theory.

Name	Medicalisation	Social Oppression	Feminist Theory	Total
Daphne	12	2	8	22
Debbie	24	19	25	68
Josetta	42	38	41	121
Kate	35	42	34	111
Marie	25	17	22	64
Maxine	15	22	20	57
Natasha	19	60	36	115
Rebecca	6	5	1	12
Total	178	205	187	570

Counterbalancing such results is the following data which would refute the suggestion that patriarchal discourse and the medicalisation of disability exclude and oppress women with Multiple Sclerosis:

Figure 8.2: Total Number of References to Positive Experiences: Foucault & Medicalisation, The Social Oppression Model and Feminist Theory.

Name	Medicalisation	Social Oppression	Feminist Theory	Total
Daphne	10	16	9	35
Debbie	14	14	9	37
Josetta	16	15	21	52
Kate	31	10	10	51
Marie	8	13	10	31
Maxine	13	18	12	43
Natasha	10	31	18	59
Rebecca	19	18	9	46
Total	121	135	98	354

Finally, to consider whether or not the impact of the experiences of patriarchy and medicalisation may reduce options more than the impact of the disease, these combined responses, positive and negative have been drawn together, to place them alongside the references made by participants to the impact of Multiple Sclerosis upon them:

Figure 8.3: Total Number of Responses to Negative and Positive Experiences and References to the Impact of Multiple Sclerosis.

Name	Negative Experiences	Positive Experiences	Impact of Multiple Sclerosis
Daphne	22	35	5
Debbie	68	37	11
Josetta	121	52	15
Kate	111	51	14
Marie	64	31	18
Maxine	57	43	9
Natasha	115	59	8
Rebecca	12	46	9
Total	570	354	89

DISCUSSION

It would be simplistic and irresponsible at this point to make a grand statement that sheer weight of numbers supports the statement that a combination of patriarchal discourse and the medicalisation of disability **do** oppress this group of women more than their progressive disease. The data total does appear at face value to support such a suggestion, but to make a sweeping statement that generalises the data in this way is to immediately make invisible the experiences of two of the participants which are the reverse of the remainder of the data.

In addition to this, the experiences of each of the women are varied - ranging from a ratio of 1.3:1 to 2.3:1 negative to positive responses. It is important to examine these 'above average, average and below average' results in terms of what each has to offer with regard to both of the research questions. In Chapter One I suggested that the degree to which the women my own region became excluded seemed to depend upon the complex interaction of four main factors. Taking into account these factors can assist with understanding the differences within the final results of this research.

Both Daphne and Rebecca have low levels of impairment and a relatively low impact from the disease itself. Both of these women have received support to remain involved in work and within their community, and both have received very few responses to their impairment in terms of 'personal tragedy' theory. Consequently, neither has developed an internalised discourse that disability is an individual problem related solely to their impairment.

Rebecca and Daphne both have had access to alternative discourses and have been supported in utilising them. Neither woman perceives dependence and independence in dichotomous terms, and both adapted work and community involvement to fit in with the demands of the disease - in this they do not deny their difference, but acknowledge and accept their needs within a changing continuum of interdependence.

The opposite experiences have occurred for Kate and Josetta. Their experiences of the disease have been much more profound, with Josetta's mostly invisible impairments requiring a multitude of daily management strategies, and Kate's secondary-progressive MS meaning she requires daily home assistance. Neither of these women have had access to a level of assistance required to enable them to remain involved within their broader communities, although it must be acknowledged that this involvement is also restricted by the impact of their disease.

Josetta, while having had access to an alternative discourse of feminism within her studies, has also experienced the highest number of experiences of Foucault's technologies of power, discourses of medicalisation and of powerlessness and invisibility within the group. The total of these experiences outweighs her strategies of resistance and positive experiences by a ratio of 2.3:1. Similarly Kate, who has a strong internalised discourse of resistance to

discourses of power and medicalisation, describes more negative than positive experiences at a ratio of 2.1:1. However, both women have utilised their alternative discourses at times to appeal or protest against oppressive situations within the welfare and medical arenas.

Natasha's experiences of the disease process have followed two extremes - from rapid progress of her MS and increasing levels of impairment in her first year post diagnosis, to a greatly reduced exacerbation rate and decreasing impairment during two years of treatment with Interferon Beta. Her experiences of others' responses to her disease and impairment in the first year reflected high levels of negative experiences. This total is decreasing over time in a new work situation. Natasha had access to alternative discourses which she utilised to resist her negative experiences, although these did not always prevent her experiencing disability as social oppression.

While Natasha's positive experiences are now beginning to outweigh her negative ones, Maxine is facing an opposite trend. While she has a diagnosis of secondary-progressive Multiple Sclerosis, she continues to manage her household and is supported to remain involved in her social and community interests. As she continues to struggle to find work however, she is more and more frequently facing patriarchal and medicalised discourses. While she utilises her own alternative discourse to good effect, the balance of negative responses is beginning to tip towards higher negative than positive levels. Maxine's data indicates she is beginning to internalise these oppressive discourses, and combined with increasing social constraints, suggests she is at risk of becoming excluded from in particular, the societal level of work.

Debbie is also facing the possibility of leaving the work environment. While her experiences of MS were, until five years ago, negligible, over the past years

she has faced a more rapidly progressing disease. While she is encouraged by her husband to remain involved in her community, she has, it would appear, internalised much of the discourse of medicalisation, and is at pains to minimise or hide her impairment.

Currently seeking treatment with Interferon Beta, Debbie depends on accessing what social policy has severely constrained; which means she faces an uncertain future in terms of her disease process and level of support to remain involved in her society, particularly as her friends have withdrawn somewhat from her. Debbie did not reveal having had access to any political discourse with which to resist her current position. She, like Maxine, appears to be 'at risk' of further experiences of social oppression, although for different reasons.

Finally, Marie, while reporting a ratio of 2.06 negative experiences to each positive, maintains a lifestyle in which she reveals her diagnosis to as few people as possible in order to remain involved in work, caring for her daughter and leisure. Marie is supported by her family, particularly her sister who also has MS, to remain involved at all levels.

Marie's experience of the disease process requires that she maintain very tight strategies of time and fatigue management, although her management of the one symptom which causes her the most distress is constrained by social policy that limits her access to funded medication. Marie, like Debbie, also faces the issue of 'remedicalisation', as if she wishes to apply for funded treatment with Interferon Beta, she must re-enter a medical system that she had all but exited in the past year.

While Marie's responses indicate a degree of internalised oppressive discourse, she also has access to an alternative discourse via her sister's very

different approach to her disease. Marie recognises this discourse is available to her - she elects at the moment not to utilise it.

CONCLUSION

Based on the data results, I would suggest that a combination of patriarchal discourse and the medicalisation of disability **can** at times oppress this group of women more than their progressive impairment. But I would further qualify such a statement with the suggestion that such oppression occurs within a context of a combination of factors coming together.

From the data above, I would contend that the greater the number of oppressive variables or negative experiences that come together at a given time or within a given context, and the fewer the number of strategies or alternative discourses available to the women in this group; the greater the measure of oppressive experiences seemed to be. In addition to this, as previously discussed, the impact of each woman's disease process may compound their situation, producing a particularly vulnerable subject position.

The next chapter presents a case study of one woman for whom a multitude of oppressive variables and her disease combined to result in such a subject position. Ruth's story draws together the impact of the discourses of the medicalisation of disability, Foucault's technologies of power and oppressive policies and practices hostile to her increasing impairment. Combined with the increasing needs created by Multiple Sclerosis, the impact of the discourses and practices she experienced resulted in Ruth's subject position becoming one of invisibility, powerlessness and worthlessness; increased dependence and exclusion from society.

CHAPTER NINE: PUBLIC POLICY, PRIVATE PAIN

INTRODUCTION

Within Chapter Two, a number of issues were discussed with regards to the impact of market driven policy upon disabled people in this country. Those issues will be revisited as they apply to the following experiences of Ruth and her husband during the last five years of her life with Multiple Sclerosis. Those five years expose the degree to which libertarian policies in this country - policies which espouse 'freedom', 'choice' and 'consumer sovereignty upon an even playing field - not only failed (and fail) to deliver such promises, but in fact result in oppression, exclusion and despair.

As mentioned in Chapter Three, among the responses to the newspaper advertisements inviting participants to join this study was one from a gentleman. James advised that his wife Ruth had died recently from complications secondary to her Multiple Sclerosis, but that he had a recording of her experiences I might be interested in. I duly sent him an Information Sheet and Consent Form, and on receipt of these, arranged an interview with him.

As it transpired, I was unable to use the recording he had, but as he had written several pages of notes in preparation for our meeting, I interviewed him about his and Ruth's experiences until her death in June 2000 at the age of 72. James offered a number of insights into how he perceived the impact of Multiple Sclerosis on Ruth and society's response to her disease. He also provided an extensive array of documents which formed the foundation of this case study. The documentation is, I will later argue, an indictment upon this country's political system - that successive National government policies resulted in ever decreasing assistance in response to Ruth's increasing needs.

RUTH'S STORY

Personal Background

Ruth and James married in their twenties and had two children. James worked for a large international company, and Ruth worked within the home, raising the two children and running the household. They purchased their own home, and life seemed fairly comfortable.

As their eldest child was working towards completing University studies, and the youngest was preparing to leave secondary school, James and Ruth were looking forward to spending time together again as a couple with few financial concerns and having guided their children into adult life.

Multiple Sclerosis

Their plans changed somewhat, when Ruth was admitted to hospital at the age of 40 years with what initially was thought to be a brain haemorrhage. After almost four weeks of 'observation', under pressure from James, they informed him (but not Ruth - she was later told by her GP's wife) that they were 99% sure she had MS. Treatment was begun with steroids and she was discharged from hospital two weeks later with instructions to 'go home, avoid stress and lead as 'normal' a life as possible'.

On reviewing this situation, James felt this was an impossibility - to lead a 'normal' life meant that Ruth was frequently stressed; she was a mother and housewife. While James was given time off work to help her initially, when he returned to work, Ruth had no assistance in the home. James felt that the stress of managing alone contributed to Ruth's disease progressing from relapsing - remitting MS to the secondary - progressive type.

Over the years, Ruth's MS followed a typical pattern of relapse and remission, with increasing impairment as the disease progressed. Despite the interruptions to life caused by exacerbations, Ruth and James managed to achieve many of their plans to travel together, including after she began to use a wheelchair for mobility. As Ruth entered the secondary - progressive stage of the disease, James used their retirement savings to build ramps to the entrances of their home, and adapted their bathroom for wheelchair access. He also began to assist more within the home.

Until the mid 1990s, Ruth's increasing needs were adequately met. A support needs assessment in November 1992 conducted by the local hospital acknowledged that Ruth required 24 hours of care, although she was still able to speak and eat with assistance, and was still continent. As the couple both wanted Ruth to remain at home for as long as possible, the hospital supported them to achieve this, providing her with personal assistance with bathing and dressing from District Nurses, home help and attendant care to a total of 19.6 hours per week. This arrangement worked well, and was further supplemented in April 1995 with the approval by New Zealand Income Support Service, under their 'Aid to Families' policy, of 28 days per year respite care to allow James a rest from caring for Ruth.

However, on the 1st of July 1995, the then Ministers of Health (Simon Upton) and Welfare (Jenny Shipley) sent out a circular letter to the families in receipt of respite care, advising that the Department of Social Welfare 'Aid to Families' programme was now the responsibility of the Regional Health Authorities (RHAs). This was in line with the *Support for Independence* document; a move hotly debated and contested by disability groups as discussed in Chapter Two.

The circular letter advised Ruth and James that families would still get relief care, and that there would be *no cut or reduction* in the number of days available. This document was the first in what would become a rapidly growing pile in James' manila folder, as government health reforms turned their lives upside down over the next five years.

Public policy - Political context

Ruth Richardson's 1991 National government budget contained long term plans for the restructuring of the health sector; which included rigidly targeted health care (Kelsey, 1993), a user pays system for prescriptions, doctors visits and hospital health services. Underpinned by liberal philosophy and free market ideology, such reforms worked on the assumptions that those who could afford healthcare would pay for it, while the state would provide a modest safety net of health care services to low income earners.

Similarly targeted were secondary healthcare services such as attendant care, home help and home nursing services, thereby placing responsibility back on to people and their families to manage health issues. According to Richardson:

Real welfare is created by people and families through their own efforts. Our redesigned welfare state will support those efforts and assist those who cannot assist themselves (1991:8).

The three stated goals of this political approach in the health sector were to improve efficiency and access, cut state expenditure on health and reduce the number of preventable deaths and diseases (Kelsey, 1993:86). In February 1992 however, just prior to the reforms being put in place, health economist Toni Ashton (1992 b) slated the scheme outlined in the 1991 budget, advising that none of these goals were likely to be met. A year later, the government had amended it's forecasts of savings of \$95 million per annum through user pays

and part charges to a mere \$14.4 million. Additionally, its anticipated expenditure on establishing these reforms had blown out from a budgeted \$15.7 million to \$82 million by December 1992 (Kelsey, 1993:86).

Within this political context of user pays and government overspending, **someone** had to pay. That 'someone' became people like Ruth and James, as the 'safety net' of provision of services began to be strung tighter. Within this political context, Ruth and her husband ran the gauntlet of a system in which 'health' became:

...simply another commodity to be bought and sold on the level playing field of its particular market place...[where] the terminally ill and the chronically poor who... could not afford the medicines, doctor's visits and hospital care which were once accepted as the entitlement of all... would simply be the casualties of the market (Kelsey, 1993:88).

Public policy - private pain

Three weeks following the receipt of the 1 July 1995 document, Ruth received a letter from the local CHE (hospital) advising they had referred her to [n1] (Community Support Services):

to see what services you may now be eligible for. (24/07/95)

Ruth was assessed by [n1], and the recommended care plan was that she receive a mere 4 hours per week care (down from her previous 19.6 hours). James contacted the hospital, and ensured (and noted on the plan) that Ruth's 14 hours attendant care and District Nursing input remained as before. This omission was to become a repetitive pattern over the next years.

Having got their hours reinstated, the couple continued on with their usual routine for eight months, when they were informed by [n2] (Community Care Agency) (01/04/96) that it had taken over from [n1]. Due to having inherited an

incomplete database from [n1], Ruth was reassessed by a 'Care Manager', following which Ruth's care hours were again reduced, to 17 hours per week, one of which was sub-contracted to [n3] (Agency providing Meals).

Ruth's needs had not changed however, and James again contacted the agency to ensure District Nursing services to Ruth remained intact, as they had again been omitted from the care plan. Additionally, the couple were advised by [n2] that 'Aid to Families' respite ceased to be effective from the end of June that year - it was to be replaced by a new system - although no details were given of what that might be.

Towards the end of July 1996, the CHE sent a letter to 'Dear District Nurse Client' (presumably Ruth), advising that District Nursing personal care services were being transferred to [n2] as 'they have the contract' (from the RHA) to provide these. Advised that Ruth had a 'choice' to continue with District Nurses, this letter advised this was an 'administrative transfer only'. As Ruth had significant medical needs, including pressure area care, James advised that they wished to remain with the District Nursing service. James checked up on the tendering processes for these contracts, and advised that:

*The District Nursing called in the lowest tender [n2] because the hospital wanted to be rid of it... so they gave it to [n2]. Then **they** said... 'Oh well, you know, because of costs... so we were reduced in our hours.*

Four weeks later, Ruth's condition deteriorated. She now required an indwelling catheter, which needed irrigation twice daily to reduce the risk of infection. She was subsequently referred back to District Nursing Services and the Incontinence Nurse.

In December 1996, James accessed one week of caregiver relief - now also contracted to [n2]. Ruth was placed in a rest home which for both her and James was a dreadful experience. James explained:

They didn't judge her on her (cognitive) ability... they judged her on MS with Stage Five (high level of physical impairment)... so she was put in with all the people who were demented, so... except for the staff there was no-one she could talk to... she was just put with all these people sitting round watching the TV without the sound on.

Based on this experience, James and Ruth never accessed this assistance again.

In March 1997, Ruth was again reassessed in terms of her care, which remained at 17 hours per week. However, care was no longer provided over weekends or on Public Holidays, so Ruth was confined to her bed on weekends, as James could not lift her on his own. He did however take on the additional catheter and bowel cares she required over the weekend, and bed-sponged her; but he added:

I know it was distressful [sic] for her when I had to change the catheter... holidays and weekends were quite disastrous. You came to dread them.

Ruth's condition continued to deteriorate. She lost the ability to swallow and developed an aspiration pneumonia (from inhaling food or fluid into the lungs). Due to the risk of further pneumonia from this, she had a PEG (Percutaneous Endoscopic Gastrostomy) tube inserted into her stomach and was fed through this tube with a total liquid nutrition replacement called Jevity. This was not subsidised by the state, so James began paying for maintaining Ruth's nutrition at a daily cost of approximately \$17.30 per day (in 1997) increasing to \$21.00 per day in 1999. (*New Ethicals*, 1996 & 1999).

In June 1997, correspondence from the RHA advised that further 'administrative' changes would come into effect that month. A new level of structure was inserted into the purchaser - provider split between the RHA and Home Support Provider Agencies (HSPAs). This was the establishment of the Facilitated Access to Co-ordinated Services (FACS) Agency whose role it was to assess Ruth's needs, recommend assistance (in consultation with her and James) to the service purchaser who contracted with the service providers. This circular letter (undated) advised:

*These administrative changes will make **no difference to the amount of support services you receive.** In fact, most consumers will not notice any changes.*

Five months later, Ruth received a letter from [n3] (FACS) advising she'd been referred for a FACS assessment. She was assessed at the end of November 1997, and the outcome of this was that despite increasing medical needs and increasing impairment, Ruth's home assistance hours were **reduced** by 3.5 hours per week and contracted to **two** agencies ([n2] and [n4] - both Community Care Agencies). James **again** had to ensure District Nursing services were still available, as yet again these were omitted, despite [n3's] letterhead showing it was under the same RHA as their CHE.

By now James was caring for Ruth 20 hours per day, monitoring her PEG system at night, turning, lifting and bathing her, and managing her bowel and catheter cares when caregivers were not present. He was beginning to physically break down. James asked a Consumer Advocacy Agency to obtain details of the complaints and appeal procedures for [n3], as these had not been supplied. The letter received back from [n3] only informed James that he could take his complaint as far as the RHA. He was not informed of the Human Rights or Health and Disability Commissions, or of any other avenues of appeal.

Unfortunately, the written outcome of James' appeal was not in the records he held, as he suffered a back and knee injury at the end of that year and Ruth was cared for in her home while he had **one week** off to recover. He advised however that they did not receive additional assistance.

In June 1998, Ruth's ability to eat was reassessed, and her risk of aspiration now included high risk of aspirating her own saliva. James had to begin regular suction of saliva from Ruth's throat to prevent this. In July 1999, the CHE advised that all District Nursing cares except catheter, bowel and wound care had been transferred to [n3] who, in a further letter, advised that:

There will be no change to the level of services you receive. Your personal care services will be transferred by [n3] to another HSPA of your choice...

Both these letters were received on the same day. Ruth and James by this stage were becoming increasingly stressed, as the two letters gave two different contact people within two different sections of the same RHA. Ruth faced a further decrease in cares, and James did not know anymore who he should contact. He described this as:

*I always got the feeling that she... well **we** were fighting with one hand tied behind our backs, and fighting shadows...*

He again appealed this decision. His letter to the CHE identifies that [n3] is a division of the RHA, as was the CHE which held all of Ruth's medical records; and reminded them that the same system that assessed her as requiring 24 hour care had reduced them to minimal assistance.

Additionally, he informed the CHE that the [n2] and [n4] caregivers were not trained to provide the nursing cares Ruth needed and that caregiving

arrangements were inflexible, which resulted in Ruth being put to bed at 4pm each weekday and having to remain in bed on weekends. Furthermore, Ruth had had to face negative responses to her condition from caregivers, or caregivers who had come from night shift too tired to do the work, or agency nursing staff who had come straight from nursing MRSA infected patients at the hospital to care for Ruth, putting her at risk of severe infection.

Finally, James appealed on the grounds that Ruth's civil rights to adequate treatment and his rights in terms of Occupational Health and Safety as a caregiver were being impinged under the Health and Disability Act. In raising these issues, James finally got a positive response - although it took a further six weeks to be settled.

Following a further reassessment, Ruth's home based cares were increased to 33.5 hours per week, to be provided by the two agencies, [n2] and [n4]. Almost immediately however, they hit a snag. Neither of these agencies provided what is termed 'invasive cares' - bowel, catheter, suction or PEG feeding. The District Nursing Service had withdrawn from Ruth's cares altogether.

Tired of fighting shadows, James and Ruth made a **choice**. They decided that they would themselves train a trusted caregiver from [n2] to perform these tasks. The caregiver agreed to take on these extra duties. The agency's response to their decision was to undertake a form of disciplinary discourse, writing:

We strongly advise against this type of arrangement to protect both your provider and yourself... By choosing this arrangement, I need you to be aware that [n2] cannot assume responsibility for any untoward repercussions... (19 /11/99).

Attached to this letter was a section for Ruth and James to sign, which waived their right to bring any claim, proceeding or action against [n2] and to not lay any complaint with the HFA. Regardless of the above, these arrangements worked for Ruth and James. It appeared that they had won one small battle in the economic war.

Another small battle won for James was that he finally, after over a year of 'user pays', obtained funding for Ruth's Jevity nutrition from the Health Benefits Authority. On 26 April 2000, Ruth's General Practitioner received a letter from the Authority advising:

This approval is not retrospective. Items dispensed prior to the effective date (01 May 2000) are a charge to the patient...

Ruth had required Jevity to physically survive since 1997. She died six weeks after the effective date above.

Personal lives, political liabilities

Over the five years prior to her death, the records showed that Ruth and James dealt with fifteen different organisations through six layers of bureaucracy. Within these organisations, they dealt with seventeen different staff and an estimated forty plus caregivers, not counting nursing home or hospital staff. Ruth endured eight different assessments, six of which resulted in a reduction of assistance to her. It appears that by commodifying health, Ruth's needs for care became a liability to the state.

Looking back on their situation, James commented:

I honestly believe now, after all these years, because... we went from stress to depression to anger and then to frustration... if you're going to tear down a woman, you'll tear her down that way.

Ruth was, I agree, torn down by compartmentalised 'care' from a rapidly fragmenting health system; by increasing needs and decreasing assistance, by the ongoing battle to get even her basic human rights to true freedom and choice recognised. As her husband, caregiver and advocate, I would suggest that James was torn down with her - both of them as liabilities to a system that was hostile to Ruth's needs.

The final hostility occurred within the hospital system. Ruth had been admitted to hospital three times in the last five years of her life. The first was for surgery unrelated to her MS. The second occasion was when she first got pneumonia and had the PEG inserted. During that admission, while Ruth was unconscious, the consultant asked James to sign a form agreeing that she not be resuscitated should she go into cardiac or respiratory arrest. James refused. On recovering, Ruth was not asked, despite having the capacity to give informed consent, what her wishes were about this issue.

During her final admission to hospital, James' decision was overruled by the consultant who advised that they believed Ruth was physically too weak to resuscitate. James' response to him was that he didn't understand - that while:

*...a coma is a coma... if you can help her out, you know you **should**.*

Medical power finally overruled James' ongoing advocacy for his wife. Ruth remained in a coma, and died a short while later of pneumonia. James felt that:

MS didn't kill Ruth.... She gave up fighting.

Personal lives, political change

The Literature Review discussed some of the debates around the *Support for Independence* document (1992). In terms of Ruth's lived experiences, the

concerns raised by Munford (1992) that disabled people could lose 'choice' were certainly evident. Ruth's choices were gradually eroded, and decisions made by professionals on her behalf as to her 'entitlements' did not reflect her needs for assistance.

James took on increasing caregiving roles with decreasing support, to the point where he physically broke down. As Ruth's speech deteriorated, he also had to become her advocate in a confusing system that was restructuring at an ever - increasing pace. Thompson and Anderson's (1996) concerns regarding intolerable pressure on caregivers was certainly evident, although placing Ruth into institutional care (despite pressure to do so) was not an option for Ruth or James as their previous experience was so negative in the rest home. Ruth's intelligence and sharp wit remained until she died - such a placement would have been inappropriate for her.

Ruth and James had visited a specialised MS centre in Australia which provided assistance for **all** aspects of life with the disease, not just physical cares. James felt that such a centre would have been more appropriate for Ruth. While there is a centre in this country, it is located in the South Island, and is, as far as I am aware, unavailable to North Island residents.

The fragmentation of the health system critiqued by writers such as Brown (1996) and Ballard (1992) was certainly apparent in the ways that Ruth and James had to manage multiple providers and purchasers, reaching the point where they no longer knew who they should approach to get the assistance they needed. In identifying and reassessing Ruth's disability in terms of the physical impairments she had, the discourse used by the fifteen organisations she and James dealt with denied any responsibility for the ways in which they contributed to her exclusion and her increased dependence.

The discourses which accompanied the multiple changes to the system couched this restructuring in the language of economic liberalism. In so doing, Ruth's subject position within the documentation changed from 'patient' (1995), to 'client' (1996), to 'consumer' (1997); and those she received services from changed from 'hospital' and 'hospital staff' to 'service co-ordinator', 'Community Support Agency' (1995), or 'Care Manager' (1996). In 1997 the language used reflected even more the market driven nature of the health sector with the 'administrative changes' (that promised 'no changes' to the services Ruth received on three occasions) resulting in more layers of bureaucracy, and the titles of the people running these organisations becoming 'manager' or 'company manager'. All vestiges of 'care' were lost from their titles.

While the discourse was couched in terms of Ruth's 'choice' and 'consumerism', the outcomes for Ruth were, finally, no choice, little spending power as a consumer and a loss of freedom. The system failed Ruth and James miserably. As the residualist 'safety net' became overstretched, both Ruth and her husband fell through it, becoming as a consequence, 'casualties of the market'.

CONCLUSION

Ruth's story might easily be 'brushed off' as the presentation of a 'worst case scenario' to prove a point that public policy impacts negatively on disabled people generally, and women with MS in particular. But six of the other women in this study have also experienced, to greater or lesser degrees, similar difficulties within the health and welfare sectors, within housing, employment or service provision.

Public policies can and do result in private pain. Discourses of oppression and the medicalisation of disability underpin current policy documents in this

country, affecting not only this group of women with MS, but women **and** men with MS, as well as disabled people nation-wide.

The provision of adequate services for Ruth and adequate support for James would not have prevented Ruth from dying. But what was provided was 'too little too late' as well as 'too little too cheap'. In telling Ruth's story, the personal impact of her experiences has been linked to the political environment in which we **all** live. Alternatives **must** be pursued, as the free market, economy driven welfare state fails us in our daily experience. The following chapter will address some of those alternatives. In doing so, hopefully we can avoid in the future disabled people like Ruth fighting to their last days for assistance which should be accepted as a civil right. In so doing, hopefully we can also avoid the analysis made below by James:

I say society failed her.

PART THREE:

OPTIONS? OPPORTUNITIES?

CHAPTER TEN: MULTIPLE CHOICE? CONCLUSIONS AND RECOMMENDATIONS

INTRODUCTION

This final chapter serves three purposes. Firstly it revisits the research questions asked at the beginning of this thesis and offers a series of conclusions in response to those questions. Secondly this chapter examines and critiques the strengths and weaknesses of this study; and suggests future directions for research into the lived experiences of Multiple Sclerosis. Finally, this chapter makes a series of recommendations drawn from the data and suggestions made by the participants themselves as to how the current lived experiences of women with Multiple Sclerosis can be improved **now** while the scientific community waits for its momentous discovery of the causes and cures of this chronic degenerative disease.

This research sought to examine how women with Multiple Sclerosis experienced disability as their disease progressed over time. Two research questions formed the basis of this study, these being:

Does a combination of patriarchal discourse and the medicalisation of disability oppress and exclude women with Multiple Sclerosis from society, thereby reducing their options in life more than their progressive impairment?

and secondly:

Do the alternative discourses of feminism and the social model of disability offer women with Multiple Sclerosis options for politicising their experiences and opportunities for empowerment and emancipation as a consequence?

QUESTION ONE: OPPRESSION?

In response to the first research question, the conclusions that were drawn were:

- A combination of patriarchal discourse and the medicalisation of disability **can** and **did**, to varying degrees, oppress and exclude six of the women in this study from society, and;
- The higher the number of oppressive variables (in terms of such discourses and discursive practices) that came together for an individual within a particular context or time, the more likely it appeared that such oppression and exclusion would or could occur. Additionally;
- These experiences of oppression and exclusion occurred within a number of levels of society, although more frequently occurred at the societal levels of the community and broader society, and were underpinned by political discourses hostile to the womens' impairment.
- For half the women in this study, such experiences reduced or had reduced their options in life (particularly in the areas of employment, adequate treatment and provision of services) at times more profoundly than their progressive impairment.
- Inadequate treatment or assistance within the womens' environments exacerbated the physical difficulties experienced by in particular, two of the women in this group. This means that the above statement could not be made for these two until the removal of multiple oppressive variables allowed them to reassess their situation in terms of whether their impairment or the oppressive circumstances affected or affects them the most.
- For two of the women in this study, the combination of patriarchal discourse and the medicalisation of disability did not impact upon them to any significant degree; neither however did their impairment, and they were not excluded in any way from society.

- In terms of the impact of the disease itself upon the women, their references to the societal responses to their disease and impairment outweighed those of the impact of the disease upon them. However, as discussed in the results section:
- At times the impact of the disease could combine with the impact of socially oppressive variables to create a particularly vulnerable subject position.

QUESTION TWO: OPTIONS? OPPORTUNITIES?

In response to the second research question regarding the application of the social model of disability and feminist theory to the experiences of women with Multiple Sclerosis, the following conclusions were drawn:

The social model of disability

- I contend that it is not only possible, but **essential** to utilise the social model of disability to better identify what needs of all people with Multiple Sclerosis are created by the disease process and what are a consequence of social oppression.
- In doing so, many of the experiences of this group of women ceased to be a consequence of 'having MS', and become defined in terms of the ways in which society contributes to or exacerbates their lived oppressive experiences unnecessarily - that is, the experience becomes **politicised**.
Additionally;
- By politicising experiences such as those discussed within the data results, one is able to identify where oppressive discourses and public policy fail to meet the needs of not only women with Multiple Sclerosis, but also men with MS. This is particularly useful in terms of critiquing the impact of public policy which in this study identified:

- A failure of welfare policy to adequately provide for the economic needs of three of the women in this study, while forcing them to continually restate their subject positions in medicalised terms and;
- A failure of employment policy and human rights legislation to ensure the additional needs of some of this group were met by their employers, or to encourage employers to action policy available to promote the inclusion of disabled people in the workplace and;
- Socially oppressive practices underpinned by economic policy hostile to adequate medical treatment of people with Multiple Sclerosis which in this study resulted in one woman being left needlessly in pain and excludes others from treatment with the only agent available in this country to halt the progress of their disease. The outcome of this is that some women in this study and others with MS nation-wide may experience unnecessary additional impairment and dependence as a result. This is a civil rights issue.
- Utilising a social model approach can also identify where empowering discourses and practices create enabling environments. This was also revealed within the data where for some of the participants, access to adequate economic, employment, healthcare and personal assistance enabled them to remain actively involved within their wider community regardless of the demands of their disease and their accompanying impairment.
- Finally, the social model of disability, in redefining disability and resituating the 'problem' of disability within the context of society, offers an alternative politics of change for disabled people and their non-disabled allies. In ceasing to locate the problem of disability within a discourse of individual pathology, not only women with Multiple Sclerosis, but disabled people generally, have available opportunities to take steps towards personal and

social action to identify and protest against issues such as those identified throughout this study.

A feminist analysis of disability

The alternative discourse offered by a feminist analysis of disability also enabled the experiences of this group of women to be politicised, while at the same time acknowledging the lived realities of the disease. This approach developed the social model of disability to include issues in which patriarchal discourse impacted on the women in this study. In addition to the issues noted above, additional conclusions arose which included:

- The women in this study experienced significant levels of invisibility, or hid their impairment in order to pass as 'normal' within able-bodied society and;
- Patriarchal concepts of 'time', 'work' and 'productivity' resulted in this group of women appearing to have a particularly vulnerable position in terms of job loss and/or pressure to leave paid employment.
- The experiences of these participants supports the suggestion that a continuum of dependence and independence (or interdependence) exists within this group and that dichotomous thinking about the concepts of dependence and independence is inappropriate.
- A feminist perspective also identified that the current arrangements for receipt of paid personal care revealed a situation where caregivers are inadequately trained, poorly paid and, it would appear, likely to come from oppressive situations themselves. Additionally, paid care appears to be inflexible in terms of when care is given or by whom. This situation is underpinned by patriarchal economic and employment policies. As a consequence, receiving care under these circumstances may constitute a significant risk for some women with Multiple Sclerosis and may increase rather than decrease their dependence.

- The experiences of this group of women supported the concept of women holding multiple subject positions, not only in terms of managing 'multiple sites of oppression' with multiple strategies of resistance, but also in terms of managing the daily changes associated with the lived experience of Multiple Sclerosis.
- Finally, this group of women did not overall, evidence having developed a politics of difference. However, what did become apparent within the data was that:
 - Access to an alternative discourse (whether those under discussion or alternative viewpoints on their experience), and support to utilise it, meant that some of the women in this study could resist discourses of patriarchy and medicalisation, and thereby politicise their experiences, either in terms of validating their own analysis of a situation, critiquing the knowledge of 'professionals' or taking action to resist or protest against oppression or exclusion. What was also revealed however was:
 - Access to such discourses was not generally provided by any of the agencies with whom the women were involved, including the Society established to support people with Multiple Sclerosis. Again I would contend that discourse is not only about what is communicated, but also about what is never exposed for the scrutiny and comments of disabled people.

The conclusions presented here were drawn primarily from the data obtained from the women in this study, combined with the theoretical debates under discussion and available previous research. As discussed in Chapter Two however, very few academic studies focus on the experiences of women with Multiple Sclerosis from a qualitative framework, and even fewer consider these experiences in terms of a socio-political paradigm. Therefore, there are a number of methodological issues which require consideration in terms of the strengths and weaknesses of this research.

STRENGTHS AND WEAKNESSES OF THIS STUDY

Generalisability

As discussed previously, the availability of academic studies which describe the lived experiences of both men and women with MS from a socio-political or critical perspective is extremely restricted. Additionally, even fewer studies are available which focus on the experiences of women with Multiple Sclerosis. The paucity of available research therefore means that there is little basis upon which to compare the results of this study with others.

While this research has at times confirmed the conclusions made in other studies (for example, Davoud & Kettle's (1980) discussions on MS and work, or Munford's (1992) work on caregiving), or the theoretical debates and analyses already presented, the results and conclusions presented here must, for a time stand alone as narratives 'from the margins'. Inherent in this statement is one of the weaknesses of this research - it is not a large, generalisable study; therefore the conclusions drawn and the recommendations which follow are likely to be perceived as a very small voice in the crowd.

This does not mean however that this voice is a less **valid** one. The narratives of this group of women add to the 'increasingly vocal' (Boyles, 1994) disability community in terms of challenging the current societal perceptions of disability as personal tragedy. Furthermore, the narratives of this group also raise valid and concerning civil rights issues regarding their treatment (or more concerningly, their frequent **lack** of treatment) which must be addressed.

In the validity of their voices lies one of the strengths of emancipatory research and this study: that the lived experiences of these individuals are brought in from the margins, and cease to be isolated, individualised experiences. Such a

research paradigm asserts the rights of these voices to be illuminated and heard.

Validity

In terms of the validity of the data obtained, a positivist paradigm would perceive the process of the data collection as a weakness in this study due to the inherent nature of human participants to 'embellish' or provide only partial accounts of their experiences. As already debated in Chapter Three of this thesis, the use of in depth interviewing was to ascertain what meanings participants ascribed to their experiences. Not only was such meaning making unable to be obtained by using quantitative methods, but the contributions of participants' own insights and meanings further contributed to the debates around the theories being presented and identified areas for future research.

The use of triangulation strategies including accessing written documents confirmed the narrated experiences of the participants and helped to strengthen construct validity. In returning the interview transcripts to participants for checking and correcting, face validity was strengthened and the risk of misrepresentation of the participants' information was reduced.

Researcher bias

I have already asserted that all research is socially constructed, and therefore reflects an inherent bias. This study faced the accusation that it was designed to support a politically pre-determined point of view. While I contend that **all** research (whether overtly or when couched within an artificial positivist framework) supports a politically pre-determined point of view, in order to avoid researcher bias influencing the data results, I endeavoured to analyse the data in terms of not only the ways in which the womens' narratives confirmed the theories, but also in terms of their resistance and strategies.

However, I must acknowledge, on reflection, that researcher bias probably **did** impact on the data analysis - although not as might be expected given the research paradigm undertaken. That is, because of the accusation of political bias made prior to the research being conducted, while completing the data analysis I was conscious of 'proving' that I had undertaken to provide a balanced analysis of the data. While that had always been my intention regardless, I believe that at times I subconsciously submitted to the concept of 'hiding disability' as discussed within the feminist critique - that any bias within the data I suspect leans more towards evidencing the strategies and resistance of the women than to the social oppression or feminist models. It is possible that a more overtly political analysis could have produced somewhat different data, although this may have been at the cost of acknowledging the very real difficulties of living with a chronic disease. Notwithstanding the above, every endeavour has been made to honestly present a balanced study within the research paradigms used.

Further research

As discussed within the results section of this thesis, the data suggested further research was possible in a number of areas. Additionally, suggestions were made by some of the participants themselves as to further research needs, which have also been included here.

A Foucauldian analysis of discourse and the medicalisation of disability prompted the suggestion that further research into the ways in which oppressive discourses are internalised could be useful. Such research may assist in identifying an awareness of when a person is at risk of internalising oppressive discourses at the expense of their own discourses or resistance. Such research could not only assist disabled people in terms of their own empowerment, but could also alert social work or social service practitioners to

the times when the people they are working with face more oppressive discourses than empowering ones. In being able to identify such times, workers can ensure access to alternative discourses which disabled people may choose to utilise rather than risk internalising oppression.

An emergent theme within this study raised the issue of a 'remedicalisation' of disability as participants are required to re-enter the medical system in order to access funded medical treatment. Arising from this discussion is the suggestion that research be undertaken to assess the impact on people with Multiple Sclerosis of re-entering a highly rigid, medicalised process in order to access treatment which should be a **choice**. Given that this study has already debated that lack of access to Interferon Beta in this country is a civil rights issue, then the enforced assessment procedures and disciplinary discourses which accompany accessing treatment are also such an issue.

Within the social oppression model, the data revealed an emerging theme that high levels of powerlessness and low levels of empowerment could result in increased experiences of disability as social oppression for women with MS. Further research in this area could ascertain whether or not such a theme is reflected within the population of people with Multiple Sclerosis. Stemming from such research, social work and social service practitioners can develop strategies with people with MS to provide alternative discourses to resist those of oppression, and in this, to offer opportunities for empowerment and emancipation.

In asking this group of women how they perceived differences between themselves and men with Multiple Sclerosis, the intent of the question was to explore a politics of difference. The responses of the participants indicates that this is an area in which the opinions of both men and women with MS should be

sought. I was unable to locate any research in terms of the different experiences of men and women with this disease, although I am aware (personal communication, Multiple Sclerosis Society of New Zealand, March 2000) that a study is currently being undertaken on the experiences of men with MS. Three of the participants in this study suggested that this area should be further researched.

Also suggested by a total of five participants, was that research into the experiences of other women with Multiple Sclerosis should be pursued and presented for all women with MS to learn from. I agree that such an analysis of the lived experiences of women with MS should be pursued further in future work. Currently however, this group of women present their experiences. And from their experiences, and the conclusions drawn as a result, a number of recommendations arise.

MULTIPLE CHOICE: RECOMMENDATIONS

The following recommendations have been developed as a result of the conclusions drawn above, as well as the recommendations made by the participants themselves throughout the research. In recognition of the detailed suggestions made by the participants, the recommendations made are relatively detailed, and include practical suggestions and choices as a starting point from which action can occur.

The recommendations have firstly been made in terms of the community level of experience for the women in this study. Following this, recommendations are made under the headings of key policy areas, as most of the oppressive experiences described within this study are underpinned by the societal level of political discourse.

Community Level

a) Work/Study

- That employers take affirmative action to promote and maintain women with Multiple Sclerosis within their workplaces, within the demands of their disease. Ways in which this can occur includes:
 - ⇒ Making use of flexible working hours / job share positions.
 - ⇒ Flexibility within the working day to allow for rest breaks or an ability to split a day's work into two 'shifts' with a break to rest in between.
 - ⇒ Provision within employment contracts in order to 'bank' time in the event that an exacerbation uses up an employee's sick leave. What this means in practice is that an employee works for example, 40 hours per week, but is paid for 36, banking the other 4 hours. This banked time is drawn on either once sick leave is used, or at times when an employee is only able to work part days when symptoms of MS are problematic.
 - ⇒ Communicating openly with employees with MS about what assistance they require within the worksite, and actioning their needs.
 - ⇒ Employers promoting honest communication between themselves and employees with MS. This includes being honest about what expectations the employer has of the employee.

- That within learning institutions, students diagnosed with MS are made aware of assistance available to them via disabilities co-ordinators in order to be able to access the assistance they require to continue studies at the pace they require.

b) Community / Community Agencies

- That community service agencies ensure that all staff are adequately trained to provide the cares they are contracted to undertake for people with Multiple Sclerosis.
- For personal care agencies this includes:

- ⇒ Ensuring adequate training about the impact of Multiple Sclerosis in terms of physical symptoms and impairments, including the invisible impairments of fatigue, pain and cognitive dysfunction.
 - ⇒ Ensuring that caregivers have training in basic hygiene and safety issues in terms of lifting practices - for the safety of both the caregiver and the person receiving care. Additionally,
 - ⇒ Ensuring that these practices and procedures are followed by caregivers.
 - ⇒ Establishing flexibility around the provision of care. It is not appropriate that adults are put to bed at 4pm in order to fit in with the requirements of the care agency.
 - ⇒ Regimes of care involve proper consultation with the person receiving care. This is not only in terms of identifying how much assistance is required by a person with MS, but also how and when that assistance will be delivered.
- For Disability Support Services this includes:
 - ⇒ Ensuring prompt provision of services for people with MS.
 - ⇒ Ensuring that any problems with equipment are dealt with promptly, without involving the person with MS in the debate over 'who will pay' to manage the problem.
 - ⇒ Providing training to all workers regarding the impact of this disease on people with MS.
- For Work and Income New Zealand this includes:
 - ⇒ Training staff about Multiple Sclerosis and other degenerative diseases in order that they understand that while the disease may change week by week, long term it will not 'disappear', resulting in a sudden ability to 'work'.
 - ⇒ Working to change the culture of the organisation which currently means that people with Multiple Sclerosis are not informed of their benefit entitlements and are made to feel that they have to 'evidence' their subject position of 'disabled'.
 - ⇒ Working to make available staff who live impairment and who have training in and an understanding of the politics of disablement.
- For the Multiple Sclerosis Society, recommendations include:
 - ⇒ Ensuring new Field Officers have adequate training regarding communicating adequately with people with MS prior to them beginning in their position.

- ⇒ Providing access to a variety of discourses of disability for members. This includes access to socio-political discourses. In so doing, members can then choose what discourses are most appropriate for them under different circumstances, rather than having these prescribed by omission.
 - ⇒ Access to information about a variety of research studies - not just those which are focusing on the cause/cure of MS.
 - ⇒ Monitoring the level of medicalised reports within the national MS journal, and ensuring that a balance of articles provides people with MS with information about 'living MS now' as well as medical treatment.
 - ⇒ Agitating on behalf of members for funded treatment with Interferon Beta as a civil **right** rather than accepting government capping of the agent, which creates a class of 'haves' and 'have-nots' within the MS Society. To support the status quo suggests support for the underpinning politics of medicalisation and Libertarian economic decision making.
- For medical and allied professionals, recommendations include:
 - ⇒ Developing an understanding of the medical and feminist models of disability and offering alternative approaches to disability, including
 - ⇒ Identifying when 'disability' exists in terms of a social model definition, rather than attempting to treat disability in medicalised terms.
 - ⇒ Encouraging and actively promoting a 'team' approach, which includes communicating effectively across disciplines in order to prevent multiple appointments and repetitive assessments. This should include
 - ⇒ Establishing a working relationship with people with Multiple Sclerosis in terms of the person with MS being a part of the medical 'team' managing their disease. This means:
 - ⇒ Acknowledging that the person with Multiple Sclerosis is the expert when it comes to their disease's impact on them. This entails consultation with them about the best options for daily management, and respecting their input as valid and valuable.

In terms of the broader political and policy implications for people with Multiple Sclerosis, the following recommendations arise as a consequence of this study:

- That current employment policies and Human Rights legislation is strengthened to **actively** promote inclusion within the workplace to enable

women with Multiple Sclerosis to continue to participate within the paid workforce for as long as they identify they are able to do so. This would include ensuring employers action the recommendations made at the community level of employment.

- That an immediate review of current contracting processes is undertaken in terms of the provision of care for people with MS. Current processes financially and ideologically devalue the role of caregiving, and with that devalue people in need of care. This has promoted unsafe care practices in that poor pay fails to attract trained staff, and training for current staff appears to be inadequate and unregulated.
- That similarly, a review is undertaken of service provision for disabled people. Current provision of services is inequitable, and service provision decreases at age 65, while needs for assistance commonly increase with age for people with Multiple Sclerosis. This results in a situation of increasing needs and decreasing assistance and leads to situations of greater dependence, exclusion and isolation for people with MS.
- That the provision of Income Support Services reflect the increased needs and costs of people with degenerative diseases in terms of medical, heating/cooling and travel costs.
- Additionally, that the provision of these services reflect a change within the 'culture' of Work and Income Service in terms of staff working proactively with people with Multiple Sclerosis to ensure that all appropriate assistance is provided, rather than people with MS struggling to obtain meagre assistance.
- Furthermore, that once a person diagnosed with Multiple Sclerosis reaches a position of requiring Income Support; once allocated this assistance, they are not repeatedly reassessed unless they themselves identify a change in their needs.

- That an immediate review is conducted in terms of the current purchasing of Interferon Beta for the treatment of people with Multiple Sclerosis. Current provision of this agent is hopelessly inadequate and inequitable. Government must examine the longer term implications of waiting for people to reach a certain 'level' of impairment before becoming eligible for funded treatment as well as forcing people assessed as 'eligible' for prescription of Interferon Beta to wait until another person currently funded is taken off the treatment. Additionally:
- The entry and exit criteria set by Pharmac for treatment with Interferon Beta are not equitable, nor are they necessarily grounded in current research. This means that people who have experienced benefits from treatment may be forced to cease taking Interferon Beta because they fail an exit criteria such as the formation of neutralising antibodies. Finally:
- Currently unfunded medications such as Gabapentin for treatment of neuralgia must be reassessed in terms of funding being made available for specific situations like that discussed in this study, and where appeal processes are adequately set up and are accessible for people who require such treatment.

CONCLUSION

This chapter drew together the results and discussion section of this thesis to present a series of conclusions which responded to the two research questions asked at the beginning of this study. The research itself was critiqued in terms of the strengths and weaknesses of the approaches used. Finally, a series of recommendations were presented which were developed from not only the data, but also from the suggestions made by the participants themselves.

The recommendations are detailed - because the multiple subject positions of women with Multiple Sclerosis are detailed. The research paradigms used

promote action in response to oppression, yet frequently academic studies are critiqued for not suggesting the 'how' of social change. The women in this study provided a large number of 'hows' in their recommendations, 'hows' which require responses in order to begin to remove oppressive variables that exacerbate the lived impairment of Multiple Sclerosis.

While science and medicine continues to explore the causes and potential cures of Multiple Sclerosis (as it has done for the past 150 years), lives are being lived **now** with the disease. Those lives can be made empowered and full of choices like the lives of Daphne, Rebecca and Natasha, they can teeter on the uncertain brink of social oppression and exclusion, or they can end in isolation, despair and oppression like that of Ruth.

The **choice** between these subject positions was and is not made by the women with Multiple Sclerosis; it is decided by the society in which we all live. **Multiple Choices** have been offered to society within the recommendations made by this study. **Multiple Choices** must now also be made available to those who live daily with Multiple Sclerosis.

PART FOUR:

REFERENCE MATERIAL

APPENDIX I: MASSEY UNIVERSITY ETHICS PROTOCOL

1. DESCRIPTION.

1.1. Justification.

Multiple Sclerosis is a progressive neurological disease affecting the central nervous system. Within the brain and spinal cord, nerve fibres are surrounded by a fatty substance called myelin which is gradually destroyed as a consequence of the disease process. The destruction of myelin occurs in many widely scattered areas of the central nervous system, and the damaged area becomes filled with hardened material, or scars called plaques or sclerosis. It is from this process that the disease is named - Multiple (many) Sclerosis (scars).

As a result of this process of demyelination, varying degrees of physical symptoms and impairment occur for people diagnosed with the disease. The disease follows a varied and unpredictable course depending on where damage is located within the central nervous system and how frequently myelin is attacked over time. It is therefore highly individualised in its course, severity and in the level of impairment experienced by those diagnosed. Multiple Sclerosis has no single identifiable cause, is difficult to diagnose and has no cure. It affects women more frequently than men, and is found more frequently in countries far south or north of the equator. Aotearoa New Zealand is therefore identified as a high risk zone for this disease.

This research aims to examine how women with Multiple Sclerosis in Aotearoa New Zealand experience disability as their disease progresses over time. Underpinning my analysis of the process of becoming impaired (or disabled) is a critique of the ways in which patriarchal discourse and the medical model of disability result in the social construction of disability. I will suggest that this construction excludes and oppresses women with Multiple Sclerosis, reducing their options in life more profoundly than their impairment does as Multiple Sclerosis progresses.

My selection of this topic developed from a long standing interest in the fields of disability and of feminist discourse. This interest became more personal when I was diagnosed with Multiple Sclerosis in 1997. My own experiences of others' responses to the rapid progress of my disease raised numerous personal questions as to how society reacted to illness and impairment. As I talked with other women diagnosed with Multiple Sclerosis, it became apparent that many of them had become excluded at several levels of society to varying degrees. It seemed that as impairment had progressed, or for some at the point of diagnosis, a process began which was driven not by the disease but by society's response to the disease and to impairment. This process had resulted in their gradual exclusion from involvement in work, leisure activities and their community in general.

While my studies of feminist thought enabled me to debate that some of these experiences might stem from patriarchal discourse, the majority of feminist writers had not applied this to the experiences of impaired women, so failed to explain adequately

the societal responses experienced by myself and the women I spoke to. Further studies introduced me to the social model of disability developed particularly by Vic Finkelstein and Michael Oliver which offered many responses to the questions left unanswered by feminist thought.

From these experiences, my interest developed further in terms of whether or not other women with Multiple Sclerosis had experienced a similar process of what both feminist thought and the social model of disability defined as oppression. The intent of this research is to gain an understanding of the lived experiences of women with Multiple Sclerosis through their personal narratives of how they understood their own process of impairment and the personal impact of society's response to it. It is also to gain an appreciation of what occurred or might occur if women resisted these societal responses.

In my discussions with local women with Multiple Sclerosis, many revealed how their experiences had become silenced - how over time, what they had to say about their lives and lived experiences was not heard by medical professionals, their workplaces, welfare agencies and the community at large. This research then, also seeks to provide a voice for women with Multiple Sclerosis, and anticipates that their narratives have much to contribute to the alternative discourses offered by the social model of disability and by feminism.

1.2. Objectives.

The purpose of this research is to study the lived experiences of women diagnosed with Multiple Sclerosis. What I hope to discover is whether or not their experiences of the disease process and the impairment accompanying it support or refute the theory that disability is a form of social oppression arising from the discourses of power and the medicalisation of the condition by society. Furthermore, I will examine the impact of patriarchal discourse on these experiences to ascertain to what degree feminist thought applies to the lives of women who live daily with this disease.

Essentially therefore, my intent is to apply the data obtained from the research participants to established theory, an inductive strategy. The research questions for this study are:

Does a combination of patriarchal discourse and the medicalisation of disability oppress and exclude women with Multiple Sclerosis from society, thereby reducing their options in life more than their progressive impairment?

and stemming from this:

Do the alternative discourses of feminism and the social model of disability offer women with Multiple Sclerosis options for politicising their experiences and opportunities for empowerment and emancipation as a consequence?

In depth interviewing of women diagnosed with Multiple Sclerosis will be used to present their personal experiences, their understanding of those experiences and the meanings they ascribe to the societal response to their disease and impairment. The primary purpose of this study is to debate whether or not feminist thought and the social model of disability can be utilised to politicise these experiences in such a way as to offer

ways by which to prevent *disablement*, or exclusion by society due to gender and/or impairment.

1.3. Procedures for recruiting participants and obtaining informed consent.

I propose to seek the assistance of women diagnosed with Multiple Sclerosis from two discreet areas of Aotearoa New Zealand, with one city and one rural area located in the North Island. In order to recruit participants I will place an advertisement in the local newspapers of these regions. The advertisement will outline the research being undertaken, and invite participants to make contact via an 0800 number, which will have a voicemail component. On leaving their name and address, a copy of the Information Sheet and Consent Form will be sent to the address with a reply paid envelope attached. Any questions needed to be answered can be done so via a further telephone call. As this will be an 0800 number, prospective participants will be able to make contact without cost to themselves.

My initial invitation to prospective participants will be to a focus group interview comprising between ten and fifteen women. From this group I will request volunteers to complete one or two in depth interviews. In the event of there being more volunteers for these interviews than I am able to interview, then I will select a sample that provides as broad an experience base as possible. That is, I will select participants to cover (if possible):

- A variety of age groups - to gain an appreciation of the ways in which societal reactions to impairment may have changed over time.
- Differing lengths of time since diagnosis was made (although this alone has little bearing on the level of impairment experienced).
- A variety of levels of impairment - to compare the experiences of those with 'invisible' impairments (for example fatigue) with those of more obvious impairment (for example, a wheelchair user) as well as to assess how society has reacted to increasing levels of impairment in individuals over time.
- Women who are in paid employment as well as those who are not, or who are in part time employment

While I hope to access participants across a variety of ages, this study will exclude women diagnosed for less than two years. My reasons for this exclusion are that it is rare for permanent impairment to be present in such a short time, and also because it is a time when people with Multiple Sclerosis are discovering how the disease will manifest itself.

1.4. Procedures in which research participants will be involved.

The most important data for this study will be information from the research participants about their lived experiences with Multiple Sclerosis, their insights into those experiences and the meaning they attribute to the ways in which both the disease process and society's responses to impairment impact upon them. Prior to the interviews I will ask the participants to complete a basic information sheet in order to obtain general data about themselves, including their age, the length of time they have had Multiple Sclerosis and the physical effects the disease has had on them.

Participants will be involved in one, possibly two focus group interview(s) as part of a small group of between ten and fifteen women (possibly less in a rural area). This interview will be videotaped and is anticipated to take between one and a half to two

hours. From the focus group, participants will be invited to also participate in at least one in depth interview, which will be audiotaped. Again it is anticipated that this interview will take between one and a half to two hours. It is possible that some participants may need to be interviewed more than once, either to follow up the initial interview, or in order to meet their needs should they desire shorter interview times due to their needs.

In both interview types, I anticipate that one interview will be required. However, as fatigue is a significant difficulty for people with Multiple Sclerosis, I will discuss with the group or individuals prior to beginning whether or not they wish to have two shorter interviews in order to manage fatigue. If they desire two shorter interviews then I will arrange that. In addition to this, I will offer a follow up interview if the participants of individual interviews wish to add further information or clarify points they have made during the first interview.

I hope to triangulate the information obtained via access to individual's diaries (should they keep one), letters and documents they have in their possession relating to their experiences with professionals due to their disease. I will not however be accessing records held by these professionals. Consent to refer to such documentation is included in the attached Consent Form (Appendix 4)

1.5. Procedures for handling information and material produced in the course of the research, including raw data and final research report(s).

Primarily data will be collected on videotape, audiotape and through written fieldnotes.

1.5.1. Videotape. The use of videotape is indicated in focus group interviews for two reasons. The first is for ease of transcription as it enables speakers to be identified more clearly than on audiotape. The second is that videotape allows an additional analysis of not only what was said during the interview, but also of the interactions, facial and body expressions that occurred between and among members of the group. The videotaping of participants would be undertaken by myself, using equipment I am familiar with and use within my practice regularly. A separate consent form has been attached which outlines how the data will be collected, transcribed and used. Videotaping will be stopped at the request of any members of the focus group, or if any member does not consent to the use of videotape, then arrangements can be made to have them participate off-camera, or audiotape will be used instead.

1.5.2. Audiotape. Individual interviews will be audiotaped with the tape being stopped at the participant's request. A separate consent form (attached) outlines how the data from individual interviews will be collected, transcribed and used .

1.5.3. Fieldnotes. Fieldnotes will also be written during the interviews, and copies of any notes written can be made available to the participant(s) at their request.

1.5.4. Access to Written Documentation. Should participants keep (or have kept) a diary, or write poetry or prose about living with Multiple Sclerosis, I will request access to these. Additionally, if participants hold copies of documentation including written reports, letters from health and disability service providers and welfare (or other) agencies which can assist in the triangulation of data, then I will also access these with the consent of the individual concerned. I will not however be accessing the participants'

personal records or files held by such providers or agencies. A separate Consent Form (attached) outlines how this data will be collected, stored and utilised.

1.5.5. Transcription of tapes. Tapes will be transcribed by a person employed by Massey University, who resides in my locality. The person employed to transcribe tapes will be required to sign a statement of confidentiality on order to best protect the privacy of the research participants.

1.6. Procedures for sharing information with research participants.

Participants, as outlined in the accompanying consent forms, have the right to see and correct any information collected about them. Following transcription of video and audiotapes, copies of the transcripts will be provided to each participant involved should they desire this. Furthermore, at the completion of the study, a summary of the final research report will be supplied to each participant involved should they wish to receive a copy.

1.7. Arrangements for storage and security, return, disposal or destruction of data.

Tapes, notes and transcripts will be kept either in a locked cabinet in my office, or locked within my home. Data stored on my computer will be accessible only by password which will not be available to anyone other than myself. Copies will not be made of written reports or letters from agencies or health and disability service providers. Copies of direct quotes from participants' diaries, letters, poetry or prose will either be returned to the participant or destroyed, whichever they prefer.

Following completion of the study, videotapes will be destroyed as they cannot be returned to a single person, while audiotapes and transcripts of individual interviews will be either returned to the relevant participant or destroyed, whichever they prefer. Results from the study will be used within the final report in summarised and non-identifiable form.

ETHICAL CONCERNS

2.1. Access to participants.

2.1.1. My initial approach to participants will be via an advertisement placed in their local newspaper. On receiving a name and address from the participant on voicemail, an Information Sheet and Consent Form will be sent to the prospective participant. No further contact will be made with the participant until a consent form has been received.

2.1.2. The Consent Form for the Focus Group interview contains a section in which participants can identify their willingness to participate in an individual interview. Where participants have indicated that they are prepared to be approached for such an interview, I will make this approach myself. In the event of there being more volunteers for individual interviews than I am able to speak to, I will select participants in order to cover as broad a range of experience as possible, as set out in 1.3.

2.1.3. I have already excluded my region from this study due to ethical conflicts. The women in this region contributed to the formulation of my research interests, but the information given was within a different context and not solicited for the purposes of this research. This would I believe, create a role conflict in terms of my current relationships with them.

2.2. Informed consent.

Information about the aims of this research will be provided in written form to prospective participants initially. This information will be clarified verbally as required. Information and consent forms are attached as appendices to this application.

2.3. Anonymity and confidentiality.

As this study will involve both focus interview groups and face to face interviews, anonymity can not be guaranteed. While I as a researcher will make every endeavour to ensure the confidentiality of participants, I am unable to guarantee that other members of focus groups might not discuss the content of the interview outside of the forum in which comments were made. Prior to the focus group interviews beginning, steps will be taken by myself to outline the need for group members to respect each others' confidentiality. Before the interview begins, I will contract with the participants of the group in order to ensure that participants will not share others' information. The Consent Form for the Focus Group Interview includes a clause in which the individual participant agrees to maintain the privacy and confidentiality of the other members of the group. As already discussed, measures will be taken to ensure safe collection, storage and disposal of data, and a transcriber will be required to sign a statement of confidentiality prior to commencing work. The final report(s) arising from this research will be summarised, and names will be altered unless participants request that their own names are used.

2.4. Potential harm to participants.

Due to the nature of the research (that I will be exploring societal attitudes towards women with impairment) and the inherent nature of the disease (its unpredictability, the fact that it is incurable and that my own presentation represents the disease in its more aggressive form) I anticipate that the process of the research may provoke difficult feelings in some participants. To this end I have included in the information sheet that participants have available a support person, either during or following an interview. A copy of the Information Sheet will be provided to any support person nominated by a participant so that they can understand the purposes and processes of this research. A Consent Form for Support Persons has also been attached to this application as Appendix 5. Additionally, during the interviewing process I will offer the participants the option to withdraw.

2.5. Potential harm to the researcher.

I anticipate that I too will be affected by the narrative of the participants. I have already developed strategies for managing my own personal responses to the experiences of impairment and of disability as social oppression. Within the context of the research, I will utilise my supervisors at Massey University in order to monitor the impact of the research upon myself.

2.6. Potential harm to the University.

In following the ethical guidelines as set out in the Massey University Code of Ethical Conduct for Research and Teaching Involving Human Subjects, I anticipate that the research, as proposed, should not harm the reputation of the University.

2.7. Participant's right to decline to take part.

Participants have the right to decline to take part in this research, to withdraw at any time, or to refuse to answer a particular question. These rights are outlined in the information sheet and consent forms.

2.8. Uses of the information.

The final report of this study will be submitted as a thesis for the completion of a Master of Social Work degree. Information obtained from the research participants will be presented within this report in a non-identifiable form. The information gained will be presented thematically rather than as individual case studies which will further protect participants' confidentiality. The results in summarised form may also be published in various Multiple Sclerosis Society or other professional publications. Data in summarised form may also be referred to in presentations at conferences, seminars or lectures.

2.9. Conflict of interest / Conflict of roles.

As a woman living with Multiple Sclerosis I anticipate that from time to time there will arise situations where there may be a conflict of interests or roles. I am committed to an emancipatory research paradigm and the principle of reciprocity which this paradigm entails. If during the process of conducting this research I am able to provide information for participants to which they do not have access, then I will do so. That is, if participants are not aware of who they can approach for assistance with issues or for additional information on how they can access services, then I will provide that information if I have it.

2.10. Other ethical concerns.

A particular area of concern I have lies within the use of the final research report in ways that may not be beneficial to people with Multiple Sclerosis nation-wide. Given that a large number of people with Multiple Sclerosis are on benefits due to their illness, and that I will be debating the right to participate in society, including the right to work, my concern is that policy makers will use the information inappropriately. That is, that people with Multiple Sclerosis will become subject to scrutiny around their ability to work *without* the supports being put in place that a social model theory would demand to enable participation at this level. While I have little control over this type of a response, it is a possible outcome I have concerns about.

3. LEGAL CONCERNS.

3.1. Legislation.

3.1.1. Intellectual Property Legislation. Appropriate literature use for the purposes of this study is legislated for under section 43 of the Copyright Act 1994.

3.1.2. Human Rights Act, 1993. This study will invite only women with Multiple Sclerosis to participate in the research. Given that the main objectives of this study are to apply feminist theory alongside the social model of disability to the lived experiences of impairment; the principles of feminist thought would support such an approach. That is, that theory about and by women is used for the benefit of women. This may however be construed to be discrimination on the grounds of gender. The Human Rights Act does not refer to research as a context or form of discrimination.

3.1.3. Privacy Act, 1993. The principles of obtaining and utilising information contained in this Act will be complied with. Information will only be obtained and utilised with informed consent from research participants. Where information is obtained from participant's copies of medical, welfare or agency letters and/or reports, reference will be made to those in a general sense, without identifying individual writers or particular localities or offices of those writers in order to preserve their privacy and confidentiality.

3.1.4. Health and Safety in Employment Act 1991. I will not be employing research assistants. A typist will be employed for the purposes of transcribing taped interviews. This person will be contracted by Massey University through the Disabilities Co-ordinator. Therefore the requirements of this Act will fall within the contract undertaken between the University and the typist employed.

3.1.5. Accident Insurance Act, 1998 and

3.1.6. Employment Contracts Act 1991. I am uncertain as to the current status of these enactment's as they are currently under review and likely to change during this year. However as I will not be directly employing research assistants it is likely this legislation will not directly affect this research. In terms of the employment of a typist, I would assume that due to the contract being undertaken between the University and the typist concerned, this would also be the responsibility of the University.

3.2. Other legal issues.

I am, at the time of writing, unable to anticipate other legal issues. Should I become aware of additional legal or ethical issues during the course of this study, I would, in the first instance, bring these to the attention of my thesis supervisors. On their recommendation I would further approach the Ethics committee to review this study.

4. CULTURAL CONCERNS.

This study will include only pakeha women as Multiple Sclerosis affects primarily Caucasian people, particularly those of European descent. African and Asian people are very rarely affected. To the best of my knowledge there are only two or three people in this country who have Multiple Sclerosis and come from a Tangata Whenua background. One of these is already excluded as she lives in my region, and one is myself.

5. OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH.

5.1. Ethics Committees.

Not applicable.

5.2. Professional codes.

As a practising member of the Aotearoa New Zealand Association of Social Workers, this research is subject to the Code of Ethics of this Association. This code emphasises my responsibilities in treating research participants with respect, in a confidential and non - discriminatory manner while encouraging their autonomy, self - determination and human rights.

APPENDIX 1: INFORMATION SHEET

179.899 MASTER OF SOCIAL WORK THESIS

INFORMATION SHEET

Massey Letterhead

My name is Sioux Green and I am a Master of Social Work student currently completing my thesis. I am also a woman who has Multiple Sclerosis. My research supervisors are Mary Ann Baskerville and Dr. Mary Nash.

I can be contacted by telephone on 0800 Alternatively, I may be reached on (025) 205 8824. My supervisors may be contacted on (06) 356 9099 during working hours, or alternatively on (06) 350 5799.

The study which I am undertaking is to record the lived experiences of women with Multiple Sclerosis as they relate to the ways in which society treats women who are disabled.

In carrying out this research, I would like to invite you to participate in one or both of the following settings:

1: A Focus Group Interview:

This interview will involve yourself and up to fourteen other women with Multiple Sclerosis from your area. The interview will cover a variety of areas in your life, and will be videotaped. The interview will take between one and two hours. All information obtained during the interview will be kept confidential, and your details will be altered in the final thesis in order to preserve your confidentiality. Videotaping will be performed by myself and the tape will be transcribed by an employee who is required to sign a statement of confidentiality.

The purpose of using videotape is because it is easier to identify each speaker within the group and prevents the transcriber mistaking who is speaking at a given point in time. Videotape will also allow me to better observe the interactions between members of the group. On completion of the interview, the camera tape will be copied on to an ordinary VCR videotape for reviewing. Only myself and the typist will view this tape. On the completion of this study, all videotapes will be destroyed. Copies of the transcripts made of the interview will be made available to each person involved in the interview if they would like to receive one.

2: An Individual Interview:

At the group interview I will invite each of you to participate in a further individual interview which will cover the topics discussed in the group interview in greater depth. In the event of more volunteers agreeing to participate than I am able to interview, then I will select a small number of people to speak with. I will base this selection on a number of factors to include the following:

- A variety of ages
- A variety of lengths of time since diagnosis
- Differing levels of impairment (or disability)

- Those who are in paid employment, part - time paid employment or not in paid employment

This interview will also last between one and two hours and will be audiotaped. At the completion of this study, any tapes will be either destroyed or returned to you, whichever you prefer. You will receive a transcript of the audiotaped interview if you would like to receive this.

In addition to these settings, I would appreciate your assistance in the following areas:

1: Questionnaire/ Information Sheet:

Prior to beginning the Focus Group Interview, I will ask you to complete a brief Personal Information sheet in order to obtain basic information about yourself (your age, marital status and length of time since diagnosis) and the physical effects of Multiple Sclerosis on you. This questionnaire is one page long and will take about ten minutes to complete.

2: Access to Diaries and Documents:

- a) If you keep or have kept a diary in which you have recorded your experiences of living with Multiple Sclerosis;
- b) If you have written poetry, letters and / or prose about these experiences;
- c) If you have copies of medical reports, notes, documents or discharge summaries;
- d) If you hold copies of letters from health and disability service providers, welfare or other agencies;

I would like, with your permission, to see these for additional information. I will not however be accessing any of your records held by agencies or medical, health or disability providers. Reference to any of your written information will be presented with your details altered to preserve your confidentiality. However, should you choose to publish any of your own writing in the future, this may then identify you as a participant in this study.

3: Fieldnotes:

During my involvement with you, I will take notes which will record in as much detail as I am able to, the following:

- a) Key points and quotes from our conversations together. The reason for doing this is to have available written interview notes as a back up should the video or audio recording equipment fail.
- b) My observations of group interactions, facial expressions and body language as audiotape in particular does not record these.

All of the information collected from the interview(s), diaries, documents and fieldnotes will be included as part of my study, although it will be presented in summarised form to protect your privacy and reduce the chances of you being identified as a participant. I am not however able to guarantee your confidentiality, particularly within the group interview, as I cannot prevent other members of the group from discussing the content of the interview. I have endeavoured to address this difficulty by including a section in the Consent Forms for the Focus Group Interview and for Support People which covers the need to respect each other's privacy and confidentiality.

All tapes, transcripts of tapes, documents and fieldnotes will be kept in a locked room or filing cabinet when I am not using them. Any documents, diaries or written information provided by yourself will be returned promptly (within two weeks) either by myself or by courier.

If you agree to participate in this research, you have the right to:

- * refuse to answer any question
- * withdraw at any time during the research
- * see and correct any information collected about you
- * request that recording equipment is turned off at any time
- * request the immediate return of any documentation you have provided
- * have another person with you if you wish to
- * ask any questions about this study at any time during your participation

As I am studying the ways in which society treats women who are disabled, some of the issues we discuss could be difficult. Should you agree to participate in this study, I would encourage you to have a support person is available to you prior to beginning each interview and during or following our interview. An Information Sheet and separate Consent Form will be provided to your support person for them to sign. Their Consent Form includes a clause relating to the protection of your privacy and confidentiality outside the interview setting.

On completion of my research, you are entitled to receive a summary of my findings if you would like a copy.

APPENDIX 2: CONSENT FORM.

179.899 MASTER OF SOCIAL WORK THESIS

CONSENT FORM (FOCUS GROUP INTERVIEW)

Massey Letterhead

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right to withdraw from this study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the undertaking that my name will not be used without my permission and that the information will be used only for this research and publications or presentations arising from this research project.

I understand that this interview will be conducted within a group setting, and I agree to maintain the privacy and confidentiality of other group participants by not discussing their input with others outside the group setting.

I agree/do not agree to the interview being videotaped.

I also understand that I have the right to ask for the videotape to be turned off at any time during the interview. I am aware that the videotape and any transcripts will be destroyed at the end of the study.

I would/would not like to receive a copy of the transcript of this interview.

I would/would not like to receive copies of any fieldnotes written during this interview.

I would/would not like to be contacted for an individual interview subsequent to this interview.

I agree to participate in this study under the conditions set out in the information sheet.

Signed.....

Name.....

Date.....

APPENDIX 3: CONSENT FORM

179.899 MASTER OF SOCIAL WORK THESIS

CONSENT FORM (INDIVIDUAL INTERVIEW)

Massey Letterhead

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission and that the information will be used only for this research and for publications and presentations arising from this research project.

I agree/do not agree to the interview being audiotaped.

I also understand that I have the right to ask for the audiotape to be turned off at any time during the interview.

I would/would not like a copy of the transcript of this interview.

I would/would not like to receive copies of any fieldnotes written during this interview.

At the completion of this study, I would prefer one of the following options to be followed with my audio tape and transcripts:

- They are returned to me
- They are destroyed

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed.....

Name.....

Date.....

APPENDIX 4: CONSENT FORM
179.899 MASTER OF SOCIAL WORK THESIS

CONSENT FORM (WRITTEN INFORMATION)

Massey Letterhead

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide written information and documentation to the researcher on the understanding that my name will not be used without my permission, that it will be returned to me within two weeks and that the information will be used only for this research and for publications and presentations arising from this research project.

I understand that I have the right to request the immediate return of all or any of the documentation I have provided to the researcher.

I understand that should I choose to publish any of my own writing in the future, this could identify me as a participant in this study.

At the completion of this study, I would prefer one of the following options to be followed with any written notes taken from my documentation:

- They are returned to me
- They are destroyed

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed.....

Name.....

Date.....

APPENDIX 5: INFORMATION SHEET (SUPPORT PERSONS)

179.899 MASTER OF SOCIAL WORK THESIS

INFORMATION SHEET (SUPPORT PERSONS)

Massey Letterhead

My name is Sioux Green and I am a Master of Social Work student currently completing my thesis. I am also a woman who has Multiple Sclerosis. My research supervisors are Mary Ann Baskerville and Dr Mary Nash.

I can be contacted by telephone on (06) 869 0500, extension 8023 during working hours or after-hours on (06) 867 8846. Alternatively, I may be reached on (025) 205 8824. My supervisors may be contacted on (06) 356 9099 during working hours, or alternatively on (06) 350 5799.

The study which I am undertaking is to record the lived experiences of women with Multiple Sclerosis as they relate to the ways in which society treats women who are disabled.

You have been asked to act as a support person for one of the participants of this study. I have invited participants to join in one or both of the following settings:

1: A Focus Group Interview:

This interview will involve up to fifteen women with Multiple Sclerosis (and support people if they require them). The interview will cover a variety of areas of their lives, and will be videotaped. The interview will last between one and two hours. Videotaping will be performed by myself and the tape will be transcribed by an employee who is required to sign a statement of confidentiality. Only myself and the typist will view the tape. On completion of the study, all videotapes will be destroyed. Copies of the transcripts made of the interview will be made available to each person involved in the interview if they would like to receive one.

2: An Individual Interview:

At the group interview I will invite each woman to participate in a further individual interview which will cover the topics discussed in the group interview in greater depth. This interview will also last between one and two hours and will be audiotaped. At the completion of this study, any tapes will be either destroyed or returned to the participant, whichever they prefer. They will receive a transcript of this interview if they would like to receive this.

In addition to these settings, I will ask the participant to assist me further in the following ways:

1: Questionnaire/ Information Sheet:

Prior to beginning the Focus Group Interview, I will ask all the participants to complete a brief (one page) Information Sheet which provides basic information about the participant and the physical effects of the disease on them.

2: Access to Diaries and Documents:

If the participant has -

- a) Kept a diary recording their experiences of living with Multiple Sclerosis,

- b) Written poetry, letters or prose about these experiences;
- c) Has copies of medical reports, notes, or summaries, or
- d) Has copies of letters from Health and Disability service providers, welfare or other agencies -

I will seek their permission to see these for additional information. Reference made to any of these documents will be presented with their details altered to preserve confidentiality.

3: Fieldnotes:

During my involvement with the participant, I will take notes which will record in as much detail as I am able to, the following:

- a) Key points and quotes from the interview - in case there is a recording equipment failure, these notes will serve as a back up.
- b) My observations of group interactions, facial expressions and body language as audiotape in particular does not record these.

All of the information collected from the interview(s), diaries, documents and fieldnotes will be included as part of my study, although it will be presented in summarised form to protect participants' privacy. All tapes, transcripts of tapes, documents and fieldnotes will be kept in a locked room or filing cabinet when I am not using them.

On agreeing to become part of this study, the participant you are supporting has the following rights:

- To refuse to answer any question
- To withdraw at any time during the research
- To see and correct any information collected about her
- To request that recording equipment is turned off at any time
- To request the immediate return of any documentation they have provided
- To have a support person with them if they want to
- To ask any questions about this study at any time during their participation

The Role of the Support Person:

As I am studying the ways in which society treats women who are disabled, I have encouraged the participants' to have available a support person. As the support person for this participant, your role will be to be available to the participant before, during and/or following an interview in order to support them should they request or require this.

Should this include attending a Focus Group Interview, it may mean that you are videotaped. If you engage in conversation with the participant during either interview, your comments will be recorded. Your comments will however be edited out of the transcript and will not be used within the final report. You therefore also have the right to request that the recording equipment is turned off prior to speaking with the participant.

If you attend a group interview, your role will be to support only the person who has nominated you. You are however expected to maintain the confidentiality and privacy of each participant by not revealing information about the participants or the content of the interview(s) to sources outside the interview setting.

APPENDIX 6: CONSENT FORM
179.899 MASTER OF SOCIAL WORK THESIS

CONSENT FORM (SUPPORT PERSON)
Massey Letterhead

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have been asked to act as a support person for, a participant in this study, and I have agreed to participate in the study in this role.

I understand that I may be asked by the participant to be available to her during or following a videotaped and/or an audiotaped interview.

I agree/do not agree to being videotaped.

I agree/do not agree to being audiotaped.

I also understand that I have the right to ask for the videotape or audiotape to be turned off at any time.

CONFIDENTIALITY AGREEMENT

I agree to protect the privacy and confidentiality of the participant by not revealing the content of her interview to any other person without her prior knowledge and consent.

If asked to attend a Focus Group Interview with the participant, I agree to protect the privacy and confidentiality of all the participants of the group by not revealing who the participants are, or the content of the interview to any other person outside the interview setting.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed.....

Name.....

Date.....

APPENDIX II: INTERVIEW FORMAT FOR PARTICIPANTS

Prior to Interview:

- ⇒ Ensure Consent Form is signed
- ⇒ Check if participant has indicated if they do not wish to be audiotaped
- ⇒ Inform participant again of their rights
- ⇒ Check to see if they have any questions and answer these
- ⇒ Check to see if the participant wishes to have a support person available, and if so, ensure this person is present, has read the Information Sheet and signed the Consent Form prior to beginning the interview

THE INTERVIEW PROPER:

On Diagnosis:

- ⇒ Who did you first tell about your diagnosis of MS?
- ⇒ What different reactions did you get from people to this news?
- ⇒ How did their reactions affect you?

Progression of Multiple Sclerosis:

- ⇒ Please tell me some more about what changes have occurred for you as your disease progressed -
 - ⇒ In what you do each day
 - ⇒ In family roles and relationships
 - ⇒ Within your friendships
 - ⇒ In work relationships
 - ⇒ In recreational activities
 - ⇒ In social outings or activities
- ⇒ Were these changes due to the effects of the disease, or because it was too hard to access other people's homes or the places you used to go to?
- ⇒ What changes to these environments would make it easier for you to participate in the activities you used to?

Paid Employment:

- ⇒ Are you still involved in paid work?
- ⇒ If not, how soon after diagnosis did you give up paid employment?
- ⇒ What was the reason you stopped paid work?
- ⇒ In what ways were you assisted within your workplace to continue your employment there?
- ⇒ Did you feel that you had to hide symptoms or problems while you were at work?
- ⇒ What assistance do you now get to manage your current roles?
- ⇒ What assistance do you need to continue in these roles?

- ⇒ If still in paid work, What assistance do you get to continue in paid employment while managing the symptoms of MS?
- ⇒ Do you feel able to approach your employer for additional assistance as your needs change?
- ⇒ Do you believe that your needs will continue to be met by your employer if they change in the future?

- ⇒ What has the response of your workmates been to any assistance you have received in the workplace?
- ⇒ What has the response of your workmates been to times when your disease has meant time off work or reduced output or hours?

Relationship with the Medical Profession:

- ⇒ Please tell me about your experiences with the medical and associated professions
- ⇒ What attitudes do they have towards your needs?
- ⇒ How do these attitudes impact on you?
- ⇒ Are you able to share your expertise about living with MS with them?
- ⇒ Are your questions heard and answered to your satisfaction?
- ⇒ Did/do you receive enough information about your disease, your treatment options and any side effects of those options?
- ⇒ Do you feel you have a choice as to what assistance you receive?
- ⇒ Do you feel you get the assistance you need to manage with MS in the home, at work or in the community?
- ⇒ What things make it difficult to get those needs met?

Relationships with Other Agencies:

- ⇒ Tell me about your experiences with other agencies
- ⇒ How do the staff of the agency treat you?
- ⇒ How does this affect you?
- ⇒ Do you believe you receive enough information?
- ⇒ Are you allowed time to process the information you receive and to have any questions answered?
- ⇒ What sort of information do you think these agencies need to work in a better way with disabled people?

Relationships within the Community:

- ⇒ Tell me about how people react to you when you are out in the community
- ⇒ How do these reactions affect you?
- ⇒ How do you respond to these reactions?
- ⇒ Are there other ways you would like to be able to respond?
- ⇒ What sort of responses would you prefer to have from others?
- ⇒ Have there been times when you believe you have experienced obvious prejudice as a result of being a woman with MS?
- ⇒ What happened?

As a Woman with MS:

- ⇒ Do you believe that women with MS have different experiences to men with MS?
- ⇒ In what ways?

On Completion of Interview:

- ⇒ Ensure participant is not distressed or upset by the interview
- ⇒ Ensure participant has available support person prior to leaving the interview, and that person is with them before leaving if they are upset

- ⇒ Check again whether the participant has any questions, and answer these prior to leaving
- ⇒ Advise participant again about what will occur with the tape and fieldnotes
- ⇒ Thank the participant for their involvement in the research

APPENDIX III: COPY OF PERSONAL NARRATIVE SENT TO PARTICIPANTS

PERSONAL INFORMATION:

Name: Sioux Green

Age: 35

Age at Diagnosis: 32

Marital Status: Single

Type of Multiple Sclerosis: Relapsing - Remitting

Frequency of Exacerbations: Prior to treatment with Beta - Interferon - every two to three months; since treatment began, reduced to between one and two per year.

Symptoms (past): Bladder, bowel, vision, balance, movement and mobility, sensation, FATIGUE

Permanent Symptoms: Vision, sensation, reduced mobility.

EXPERIENCES OF LIVING WITH MULTIPLE SCLEROSIS:

On Diagnosis:

When I was finally diagnosed, I told no-one for a day or so - my mum was at the hospital appointment with me, but hadn't come in to see the neurologist. I think he said "Multiple Sclerosis" about ten times during the conversation, but after the second time, told me he wanted me to go to the day ward to be catheterised before he made a decision on which medication to use for my bladder symptoms. After he said that, I didn't hear anything else, because I was worried it would hurt! At the day ward, mum asked me what he'd said. I couldn't remember! She was the first person who knew, and was amazingly supportive.

I didn't want to tell people straight away - I wanted time to just absorb the news and get my head around what that meant to me. But I'd been given such a hard time from management at work about my sick leave that year that I felt I had no choice but to talk about it. Instead of telling the manager straight away, I took in morning tea for the team I was part of. They had been really supportive of me in the months prior to my diagnosis, so I felt they should know that support wasn't in vain. I told them I had MS and what that was. My supervisor was there, so I knew the message would get back to the manager!

Most of my friends and family were told in a Christmas letter a few weeks later. I decided that this way I wouldn't have to tell people over and over again, and that if they couldn't handle the news, at least I didn't have to try dealing with their reactions. A few of my close friends who had supported me during the months of tests and doubts prior to diagnosis I told in person, because I felt safe in the knowledge that I wouldn't have to then support them.

Their Reactions:

Most of my family were really great. My immediate family were as relieved as I was - our fears had been that I had one of the diseases which would kill me within the next few years, so MS wasn't so frightening. That didn't mean they weren't concerned and sad about it being an incurable disease, but they were

pleased that I wasn't likely to die soon. Some of my extended family couldn't handle the news - one reaction was that it might be something inherited - and there was a lot of discussion about which 'side' of the family it may have come from! Others were concerned I would end up in a wheelchair which to them was a fate worse than death. Overall though, there was just support from them all.

My close friends were awesome - very practical and down to earth about it all. Many didn't know what MS was, so asked me about it, or contacted the MS Society or the library to find out about the disease. After I wrote my Christmas letter telling about the diagnosis, a few of my friends and acquaintances no longer contacted me. When I happened to be in their area, I made contact with them, but it became really obvious to me that they were no longer comfortable around me. With a few of them I just brushed it aside as being their problem, but with a couple I felt really hurt, because I believed our friendship was strong enough to manage this.

Perhaps the most difficult reactions to deal with were those of management at my former place of work. I went back to work ten days after diagnosis (I had experienced an exacerbation which confirmed the diagnosis), and that morning was asked to meet with my manager and supervisor - immediately. I had no time to organise for a support person to be with me, and as soon as I confirmed that I had MS, I was given instructions to accept a contract for half time work with no sick leave provisions. When I protested that I felt that I was making a good recovery from my exacerbation and felt I could not only build up to full time work, but also continue with my studies, I was told to "Be realistic" by my manager. Fortunately I refused to agree to anything until I had seen both my physician and my lawyer!

How their reactions affected me:

Those who supported me were no surprise to me. Many of my friends and family have very down to earth attitudes towards illness and impairment, so this was of great use to me in coming to terms with having the disease as well as during the progress of my MS. A few of the reactions of others created a sense of loss and dismay for me, as I felt at that stage that essentially I was the same person.

The response of my former employer totally blew me away, because my attitude was that now I knew what was going on, I could begin to figure out ways to work alongside the disease. My expectation was that they would do the same, and that problems could be worked out - particularly as they claimed to be an equal opportunities employer. I was devastated by that meeting - that within the space of a week, I'd become only 'good enough' for half time work and that my study goals were now unrealistic. They also raised whether or not I could safely make decisions in my work - I had, it seemed, become a liability to them. In some ways, when I look back now, I think I should have expected that response - while I was going through the process of being diagnosed, they had implied that I was abusing sick leave, and that the 'problem' was all in my head (well it **was** I suppose, given that MS attacks the brain and spinal cord!). Even so, I felt as though I had now become an even more difficult problem for them

to deal with - if they'd been able to prove somehow I was abusing sick leave, they could have got rid of me...

Progression of Multiple Sclerosis:

Over the past three years I have faced extremes from the disease. The first year following diagnosis was indescribable. I experienced a rapid series of ferocious exacerbations which occurred within months of each other. Five months after I was diagnosed, I had an exacerbation which left me so weak I had to use a wheelchair. The chair was wonderful in that I noticed an improvement in my fatigue levels - I could last longer than four hours before heading back to bed!

A lot of changes in roles and relationships occurred during this time. Within the space of a year I had gone from being a 20 hour day workaholic to managing to stay awake four to six hours each day. My mum picked up all the household jobs, and family members rallied around to help in the gardens of my home. Mum also became my unpaid driver - due to having double vision I was unsafe to drive.

Every two to three months I ended up in hospital with a further exacerbation. I reached the point where I needed a caregiver to carry out exercises on my arms and legs to prevent contractures - I had become very spastic. My cousin Tricia came to my home three times a week to do these - I insisted that a member of my extended family be trained and paid to do this, as the expectation was that my mum would also pick this role up - and in an unpaid capacity. My time with Tricia was positive, as we got to know each other a lot better over the next year, particularly as neither of us foresaw that she would suffer a brain haemorrhage the following year, or that the stories and family history she told me as we worked together were being indelibly etched on my mind to later tell her children.

My friends stayed close to me and altered their own social calendars to fit in with the demands of the MS. Knowing I could not manage going out in the evenings, they arranged to meet with me for morning teas or lunch instead. Others called in the early afternoons and just sat talking while I rested. Joining the local MS Society allowed me to meet with others once a month for lunch which I found encouraging as they shared lots of laughs and helpful hints about their management of the disease. In spite of this, my social life deteriorated markedly.

Within my workplace my colleagues remained supportive overall, in spite of extremely negative and destructive responses from management. My working day was reduced after months of struggle with those responses. In the months prior to leaving this job, a number of workmates commented on how my supervisor and manager were treating me, and at one point, half the site had decided they would strike illegally if the manager sacked me.

My recreational activities changed significantly. Prior to the first symptoms of my MS, I had been learning to fly, and was studying towards gaining my private

pilot's license. With the advent of double vision, I was immediately grounded from flying. I was also very involved in the outdoors, camping and tramping, particularly with the Girl Guides. Initially tramping became too difficult to do, although with the help of the girls and their parents or other leaders, I still managed to run camps, including after I began using the wheelchair - at times my trusty wheelchair resembled a mud - covered mountain bike!

Towards the end of that first year post - diagnosis, I was approached by my local MS Society who told me they wished to fundraise for me to receive treatment with Beta Interferon. At that stage, Pharmac refused to fund Interferon treatment, and it was felt that if I waited for the National Government to fund them, it would be too little too late for me. I was bordering on a diagnosis of secondary - progressive MS which would eliminate me even if Pharmac did fund the medication. The Interferons had very quickly become my only option for slowing down the rapid progress of my disease, but the cost was totally out of reach for me.

I weighed up the options of trailing Beta Interferon, including that it might not work for me, as well as the cost in terms of the loss of privacy such a move would entail - to obtain funding, my details would be shared with a lot of people I didn't know. In the end, I decided I had little left to lose by accepting this offer. Funding was secured for the first year of treatment some four months later, and I began treatment almost exactly one year after my diagnosis.

I have, since beginning the treatment, experienced a gradual return to good health. The rapid exacerbation rate has decreased to an average of one to two per year, with a faster recovery rate after each one. Each exacerbation has been less severe than that first year, and I now experience very little additional impairment with each one. This biggest effect for me that I noticed within weeks of beginning treatment was that the mind numbing fatigue that I experienced daily reduced remarkably. With the benefit of this, and with remaining so well for longer periods of time, I began a gradual physical recovery. I now work full time again, and walk short distances with a cane.

It has been fascinating to me to see how people have reacted to my recovery. In some ways it has been difficult for my family to have me reclaim some of the roles I relinquished during that first year. In other ways there is a belief that I am 'back to normal' now, and I have had to remind people that the disease still impacts on me on a daily basis. The expectation that has developed from many quarters that I should now be 'normal' has perplexed and frustrated me at times.

The most difficult of these expectations has been that I should 'walk'. From about the end of the first year of treatment, pressure arose from several groups of people that this 'wonder-drug' should somehow enable me to walk. I had never totally stopped walking, and while it was (and still is) unbelievably exhausting, it had not completely disappeared. It seemed to me that while I looked so ill the previous year, people perceived my chair as a tragic but necessary evil - to me it was a liberating form of mobility. As I began to look

better, the chair became to others some sort of cop-out: to me it remains a liberating form of mobility - particularly over distance and when I am fatigued.

It is intriguing to find that only now that I have developed (for the most part) a true understanding of the limits this disease places upon me, and have adapted (most of the time) my life to fit in with MS' unwelcome presence, some people believe they now have some right to expect more! Admittedly, I have responded to the treatment in ways that I never expected, but that may well be where the clues lie in these responses - I read a lot about Interferon before I began it, I felt I nothing to lose by trying it, and my hope was that it would enable me to feel **well** rather than enable me to walk - I was (and am) quite comfortable with my wheels, and if I remained that way, it was fine by me. Others dared to hope for more perhaps - and my concern is that this was prompted by their discomfort at my obvious impairment.

Were these changes due to the effects of the disease, or to the environment?

In the first year post-diagnosis, I would have to say that most of the changes that occurred were due to a combination of the effects of the disease, as well as the enormous stress I faced within my former place of work. It is well known that high levels of stress can impact on any disease, but numerous studies have focused on ways stress particularly affects MS. Looking back on that first year, I am quite convinced that the working environment I was in contributed to the rapid progress of the disease.

Once I began using the wheelchair, particularly as I began to improve, I became more and more aware of a sense of being shut out from areas of my community - many shops were inaccessible either due to steps and narrow doors, or because they were too cluttered to move in. If I wanted to go to the pictures, I had to phone in advance to see if the movie was being shown in an upstairs or downstairs theatre - with no lift, if it was upstairs, I couldn't see the film.

Moving around the central business district became a form of obstacle course - high curbs and sloping footpaths meant pushing the chair with one arm until it fatigued, then finding a curb that wouldn't throw me out of the chair and crossing the road to the opposite sloping footpath, pushing the chair with the other arm until **that** one fatigued, and repeating the whole process - sometimes I had to cross the street so often I almost doubled the distance it took to get to my destination.

Friends' homes were often difficult to access with the wheelchair, and remain so with crutches. This did not necessarily stop me from visiting however - they had no problem hauling me and chair or me followed by chair up their steps. I think I struggled with this issue more than they did, in dealing with the embarrassment of being carried.

One event which really appalled me was when I was called up for jury service. The court room was up two flights of stairs, and I rang to check about access

(tell me I ask, do non-impaired people ring ahead to see if they can get into a building? I doubt it!), to be told I was excused from attending as there was no lift. When I told the court registrar I believed this was not good enough as it prevented me from carrying out a civic duty, I was quickly put on to the courts manager. He agreed with me, and suggested I complain formally, as they had been requesting a lift for some years. Interestingly, had I been a defendant, the court would have used a ground floor courtroom - but would not do so for a potential juror. I did complain - it was a year ago now, and at the time of writing there is still no lift.

Access was also an issue within my former workplace. There was lift, which broke down every Monday - with me inside it. From the time I began using the wheelchair, until six weeks before I resigned, this was a regular occurrence. Every week I complained to the administration supervisor, who (for the first few weeks) phoned the lift repair company. When they arrived, the lift would work normally, and nothing further would be done. Fortunately people witnessed this each Monday - or I expect I would have been accused of making it all up. It reached a point where I became increasingly stressed each Monday - I don't enjoy being trapped in a lift, dangling in space between floors.

After months of dealing with this problem, the lift completely broke down. I was unable to get to the office at all, which meant I was losing more time from work. My supervisor started complaining that I was causing further problems because I was not at work... I duly turned up for work and for the next two days **dragged** myself up the stairs. I felt utterly humiliated, and by the time I reached the top, utterly exhausted. On the second day, a colleague of mine arrived to find me halfway up the stairs, crying with frustration, humiliation and fatigue. She helped me get to the top, then marched into the manager's office and told her that if I didn't complain to the Human Rights Commission, then **she** would.

The manager asked me to write a memo about the problems I'd been experiencing with the lift. I was somewhat surprised that she claimed to be unaware of the problem, as I had assumed the administration supervisor was required to report such matters as they would constitute a risk. I felt as if I had to 'prove' somehow that my experiences were real with the lift. I wrote the memo, and was promised the lift would be repaired. I was then **sent home** because I was now considered a 'risk' until the lift was fixed!

As I prepared to leave, I wheeled past the front office, and overheard the administration supervisor reading my memo aloud to the office staff. She laughed while reading it, saying, "I didn't believe her, so I stopped phoning the repair people". If I hadn't been so exhausted that day, I would have vented the rage I felt at hearing this. The lift repair company phoned me and discussed the problem. I quickly discovered that after a fire in the lift some time before, to cut costs (at the request of my employer) they had not replaced a thermostat - controlled heating system which heated the oil in the lift machinery. Over each weekend, the oil became very cold and sticky as a result, which meant that every Monday, the first time it was used, the lift jammed. Due to **cost cutting** five months of my life were made unnecessarily miserable.

Changes needed?

In my ideal world, all homes would be easily accessed, as would all shops, theatres, workplaces and district courthouses! Recent changes to parts of our CBD has improved the slopes of the footpaths for a few blocks, but most of the city remains hard work to get around in a chair. Access to and within shops is really only a matter of good management and planning - I didn't like cluttered shops before I began using the wheelchair, and well spaced displays not only make it easier for access, but are sensible sales decisions. At times however, it appears to me that the legislation requiring buildings to be accessible is negotiable.

There are some activities I know I still couldn't do, no matter how many changes are made to the environment - flying is an example. While plane controls can be altered so the plane is flown only using hand controls, double vision and piloting a plane do not mix! While I joked at the time that I had a 50% chance of getting the right runway, landing a plane requires a level of vision I don't have. But better footpaths, better access to buildings and leisure areas (for example, our Olympic pool won't put in a permanent ramp to the pool because it will lose its 'Olympic Status' - in a city that will probably NEVER host the Olympics) would mean that people like me could be more involved in our communities.

Employment:

I have also experienced two extremes in terms of responses to my MS within my working environment. In my former place of work, that first meeting with my manager and supervisor post - diagnosis was the beginning of what became to me, a matter of survival in what felt like a 'cold war' zone.

This occurred on a number of fronts: firstly there was undue pressure placed on me around how much sick leave I had taken, which meant that I returned to work after each exacerbation of MS before I had recovered. Secondly, I was expected to carry a caseload equivalent to one and a half full time positions on half time hours. I was constantly monitored and subjected to scrutiny that other workers did not have to endure. I was not supported within my working environment to be able to work effectively - in a physical and psychological sense. And finally, I was expected to deal with the multitude of daily negative responses, subtle put - downs and communications between management and myself due to their discomfort at being confronted by someone who was so blatantly physically impaired. My manager for example, would see me in the corridor, and her lip would curl in a silent sneer. My supervisor would claim (as a union representative) that I was 'entitled' to take sick leave, then would write memos complaining about how difficult this made her job (as a supervisor).

In a physical sense, areas of my workplace were inaccessible to me - not always because of the design of the building. In order to access the files and stationery in an office, all that was required was for the administration

supervisor to move her desk back 5cm. It took six months of requests and complaints about her refusal to do so before finally, in exasperation, I announced to her (and whoever else was present) that in South Africa such behaviour was called apartheid - exclusion due to colour - and that I wondered what **this** might be called - exclusion due to disability. Those who witnessed my outburst put pressure on her to move her desk. The day I handed in my resignation, she promptly pushed her desk out, again blocking my access.

I had difficulties with double vision so was unable to drive. My manager refused to make arrangements for either a driver or taxi cabs. In the first couple of months I therefore cycled to meet clients. Once I began using the chair, that was no longer an option, which meant that I, as a child protection social worker, could no longer monitor the safety of children on my caseload. I spoke with my clients about this, and amazingly, 95% of them agreed to come in to the office with their children to see me there - and true to their word they did. I look back on this now, and I think they recognised my oppression before I did - they had experienced the same scrutiny, sense of being set up and double talk as I was. In spite of their response, I became increasingly stressed about the risk this placed children and myself under. I felt I was being set up, and was angry that due to the response of management to my impairment, children's lives were being placed unnecessarily at risk.

My team mates remained supportive of me, although my supervisor undermined that at times, by telling them I was carrying a lighter workload and had not been allocated any new cases. When I heard this, I suggested they check the facts they did, and were horrified that not only did I have the second highest load (on half time hours), but that for three months in a row, I'd been allocated the most cases in the team to manage. While a group within the office committed to walking out if I was sacked, they were essentially as paralysed as I by the ongoing situation. I now refused to see the manager without my lawyer being present, so costs began to mount up and place extra stress on me. Since I couldn't afford to have her present at supervision sessions, pressure increased from that quarter - to the extent that I suggested we tape our supervision so that I had a record of what was said (she refused, strangely enough, saying I should trust her!).

I finally reached the point where, after receiving a memo from my supervisor outlining how much they'd gone out of their way to help me and the cost this had placed on her and my team - and realising I didn't even have the energy to respond, I recognised I was being set up to fail miserably, and that it was only a matter of time before I did just that. I began instead to look for work elsewhere. The day I handed in my resignation at that place was one of the most empowering and satisfying experiences of my working life.

My current workplace has been an entirely opposite experience. I spoke very openly about the impact of my MS and was obviously still very unwell when I first met with my current manager. My new manager was left in no doubt about what could happen, given the previous year. Her response was positive, proactive and tremendously empowering. She set up a meeting with the Human

Resources manager to arrange alterations to the collective contract which enabled me to work flexibly, and to 'bank' time, so that if my sick leave was used up by an exacerbation, then I could draw on the banked time as a back up. What this meant was that I was employed in a .9 position, but given the opportunity to work the extra four hours to make up a full time position. The extra hours weren't paid to me, but were 'banked' as a form of accrued leave.

She was also incredibly empowering in that her expectations of me were, that as an experienced professional, I would arrange my work days to fit with my fatigue levels and the demands of my disease. If this meant working flexible hours and taking regular rest breaks, then I was expected to time - manage these. She also expected that as a professional, I would also identify and clearly articulate my limits. The team I joined were fully aware of the arrangements we made and supported them.

Together we went through my working environment and I identified what additional aids I needed. My manager arranged a separate office/clinic room combined so I didn't have to expend energy travelling from one part of the place to the other - which was no mean feat, as space was at a premium! The additional aids I required were arranged before I began my new job, which meant that on the day I started work, my workplace was entirely accessible for me. On the occasions I needed to visit the community, my taxi fares were reimbursed, and later when my vision was reassessed and I was able to drive again, her immediate response was to enquire as to whether I needed an automatic rather than manual drive.

At first I couldn't quite believe my luck - in fact, I distrusted it a little - I had emerged from the previous worksite having begun to take on board the negativity of my daily struggles. I had begun to believe I was somehow a lesser person because of my impairment, despite my education, my knowledge of the theories around my experiences - and now, as I faced an opposite response, I kept waiting for the axe to fall, for the 'Yes, but...' responses.

That hasn't happened. In fact, as time has passed, and I have recovered, my manager has continued to be proactive. I remained so well in my first year at my new workplace that I banked a considerable amount of time. Knowing I was working on my thesis this year (and certainly not thinking that I was unrealistic in doing so), and being aware of the additional stresses that would entail, she suggested that I regularly use that banked time throughout the year as a 'preventative' - I did, and it has worked!

Instead of feeling that I had to hide my symptoms and try to be 'normal' to avoid additional scrutiny, I have been encouraged to listen more to my body and to take time to achieve what is best for my health. Combined with the effects of treatment with Interferon, this has enabled me to continue in full time paid employment **and** to succeed in that. While there are still times when, despite every assistance, the MS leaves me face down on my desk, I no longer fear those times, being secure in the knowledge that I can honestly admit these times, and rest; to prevent myself from getting back into the downward spiral of

forcing a sick body to continue, and thereby making things worse. I feel sure too, that should my condition deteriorate, I can approach her and readjust my work regime to take into account my changing needs.

I am never certain that this will remain however. I know that my manager is something of a rarity - if she left the organisation, my position could come under threat, particularly if she were replaced by someone whose attitudes were the same as my previous worksite. She personally made the effort to take the 'risk' (and it **was** a risk at the time) of employing me, and personally took the time (about four hours of work) to arrange my current situation. A manager more intent on 'outputs', more rigid about time and timekeeping would most likely have a very different approach. In response to that, however, my flexible arrangements have meant that I have been able to meet all the required outputs and carry an equivalent load to my peers - just in a different way!

Sorting out a working arrangement where I am trusted not to rip the organisation off, and am not being constantly scrutinised and measured against my colleagues has meant that I am far more committed to ensuring that trust has not been misplaced. I have developed my working day to ensure I work effectively, both within the limits of the disease, and within the requirements of a large healthcare organisation.

Relationship with the Medical Profession:

I have been incredibly fortunate in terms of my involvement with the medical profession. Prior to being diagnosed, I had convinced myself I was stressed, or 'burnt out', particularly as all the tests they were doing showed nothing. The physician I saw was very honest in saying he didn't know what was 'wrong', but was also very clear that it was **not** because I was stressed - while stress wasn't helping matters, it wasn't causing the neurological problems I was experiencing. That didn't prevent me however from calling him 'Dr Do-Little' (and the visiting neurologist, 'Dr Do-nothing') as I wasn't particularly interested in what 'label' I had, I just wanted them to fix it so I could get on with my life!

Since diagnosis, I have developed a solid working relationship with my General Practitioner, Physician, Physiotherapist and the first Occupational Therapist who was assigned to me (she left a year later). I 'sacked' the visiting neurologist - I saw him so infrequently that every visit seemed to be a start from the beginning rather than a continuation from previous contacts, which I found disconcerting and disempowering. As I had so little control over what this disease was doing to me, it was vital to me to have some control over what everyone **else** did to me. I also 'sacked' the next Occupational Therapist, as she didn't fit in with my line of thinking, which, by the time the poor woman began working with me, was very political in terms of the ways in which impaired people are treated by the medical professionals involved with them.

I think one of the main reasons for my good experience with this team (who I jealously guard!) was due to my having been exposed to the Social Model of Disability and the work of Michael Oliver and Jenny Morris. In fact, at the time I went into the wheelchair, I was reading Oliver's wonderful piece on the

sociology of walking (*Understanding Disability: From Theory to Practice, 1996*), which I am certain helped in my adjusting so rapidly to my new situation. I had also developed an interest previously in Michel Foucault's *Archaeology of Medical Perception (The Birth of the Clinic, 1973)* which meant I approached the majority of my involvement with these professionals in an assertive way. I was able, at a very early stage in my disease, to articulate how I wanted to be treated, and my expectations of them.

I was also very fortunate that all of them are enlightened people who are not afraid to be challenged about the ways in which they approached things. I think I've converted my Physiotherapist to the social model of disability, and both my GP and my Physician work collaboratively with me in managing the MS while I manage my life. Their approach is very empowering for me, and while they might not necessarily agree with my politics, they have respected what I contribute to our working relationship, and in doing so, ensure that any decisions made are informed, and mine to make.

This is not to say I didn't at times resent the intrusion into my life and home of multiple professionals, particularly within that first year. Sometimes it seemed as if my body was no longer mine - that it became more and more the property of those professionals who were treating it, measuring it for orthoses, wheelchairs, alterations and gadgets for my home, assessing it for exercises and caregivers and so on. While each and every one of them did their best to be as unintrusive as possible, there were times when I felt, like MR Gallagher (*Just A Head, 1998*), that I was 'just a head' stuck on a body that, for a time, had been handed over to medicine.

Overall however, I have felt heard and respected by the team I now work with. I am able to approach any one of them with concerns or questions and have those answered fully. Treatment decisions (including those of refusing an offered treatment) have been my decision in the end, and have been supported. I am in the unusual position (unlike many with MS) of not having experienced poor treatment at a personal level from those involved in my care. This does not mean however, that I have not critiqued their involvement from a political or Foucauldian perspective!

Relationships with other agencies:

I have not had to deal with too many agencies in addition to the medical people I work with, which I am glad about, because my experiences in one or two areas have really exposed to me the extent of the fragmentation of the health system. The first encounter I had with this was the process of getting a caregiver to do my exercises:

- Firstly, the Physiotherapist assessed me and decided I needed this service.
- She sends off an application for a **further** assessment by those who pay for this to occur.
- Their assessor (who happened to be a lovely woman) came to my home, and waded through an **eight** page questionnaire, many of the questions had nothing whatsoever to do with my needs. The assessor admitted, when I asked her, that she was not a physiotherapist, and couldn't 'overrule' what

the physio had recommended anyway. (My next question **had** to be, 'what then, was the point of spending well over an hour doing this questionnaire?')

- Their assessor approved the application - in steps a third party - the organisation who are contracted to provide the service. I had a 'choice' of two - my **real** choice was that I wanted my cousin to do my caregiving.
- She in turn is contracted by the agency of 'choice' to provide the care - but who is she trained by?
- You guessed it - the Physiotherapist who made the decision in the first place!

This process took several weeks. It may seem rather simplistic, but to me it seemed that it would be much quicker and less costly if the following occurred instead:

- Physio assesses that I need a caregiver to do my exercises. She advises me of my options regarding caregiving services and I decide what I would like.
- Physio contacts the Agency (if there **must** be one) who contracts with my caregiver.
- Physio trains the caregiver (It takes an hour or so to train a new caregiver for me).

Estimated time? Provided the agency who contracts with my caregiver doesn't muck around, the whole thing could be set up in a couple of days.

But wait! There's more! Perhaps the most frustrating event for me was when I had a waterlift installed so I could access my home. It went something like this:

- The Occupational Therapist assessed that I needed the waterlift at my home. This is no small purchase, at around \$4000=00, and I had debated for over a year whether or not I could do without it.
- She sent off the paperwork to the provider of money for said goods - who agreed to pay according to the O.T.'s assessment.
- A local tradesman was contracted to purchase the lift and install it - which he did, to the specifications outlined by the provider, based on the O.T.'s assessment and measurements.
- I was sent a form to sign to say I was happy with my shiny new lift!

It sounds deceptively simple, except:

- I wasn't happy, because none of us realised that the placement of the lift on my property created a safety hazard for small children and, as we later discovered, to myself. The lift had no safety mechanism if something got jammed between it and the patio as it was rising, which meant it effectively became a guillotine as it slid up to the patio edge.
- I informed the O.T. of my concern, who did some phoning around and told me that to correct the problem would cost more than her application had estimated; it was therefore my responsibility to pay for it to be made safe.
- I phoned, then wrote to the provider, expressing my concerns. At that stage I was more concerned about the safety of my neighbour's children than my own. I received the reply that the safety of others was my responsibility - just as if I'd installed a pool, I was responsible to ensure it was childproof.

Strangely, they couldn't accept that installing a pool for leisure was somewhat different to being able to get into my own home ... without someone's child being killed by the thing while I was out.

- I said I was still not happy. By now I smelled a political rat - the 'all care, no responsibility' (without the all care part). I refused to sign the form until this got sorted out.
- In the interim, I became caught in the crossfire between the three parties in this mess. Because I wouldn't sign the form, the provider wouldn't pay the contractor who bought the lift and did the work. In my mind, he had completed his part of their contract, and it was an issue between him and the provider - he didn't see it that way, and began harassing me to sign the form - to the extent where I told him to leave the property before I called the police, as he had become very threatening and verbally abusive.
- I made a complaint to the O.T. about the contractor's behaviour (which had been witnessed by two other people). Her response was that she couldn't do anything about it, as he was the only one in town who installed these lifts...
- Further correspondence went to the provider, after I got caught in the contraption myself. Finally a reluctant agreement to pay an extra \$120=00 to create a safety barrier, using materials I already had, **and** the tradesperson above.
- I refused the tradesperson, and made my own arrangements with someone else who agreed to do the job for \$100=00.
- Finally agreement! Everyone is happy!

Except... before the extra work could be done, I had to move house. The lift was not needed at the new house, so was passed on to another person who is now happily using it. But the final blow was yet to come:

- The O.T. informs me that I'm not 'not entitled' to any further access assistance for the next five years.

The whole sorry saga took up several hours of my time over a period of almost six months, not to mention the fear I experienced at being confronted by an irate tradesman, threatening to take the lift away and give it to someone "more deserving" (among other things) if I didn't sign a form saying I was happy when I wasn't!

No wonder people give up and shut up - the fragmented splits between assessor/purchaser/provider and consumer meant that an unanticipated safety issue became 'my responsibility' - I was responsible for my own and everyone else's children's safety, I was responsible for the extra costs, I was responsible for the tradesman not getting paid, and so on. I do not accept responsibility for these factors just so that I can get in and out of my home. I also do not accept that I must now 'pay' for the next five years for moving house and the lift being passed on to someone else. That person got the lift at little extra cost to the provider - the lift was already here, the extra cost revolved around installation.

The message to me was very clear - 'We are happy if you are happy. If you are not happy, we'll make your life even more miserable, by making it your fault that you're not happy'. Well, that's how it seemed at the time...

Relationships within the Community:

I am fortunate, for the most part, to live in a relatively close community where many people know me and accept me as being me despite the many changes I've experienced over the last years. What was difficult at times was people who didn't know me well pitying me because I used the wheelchair, and having to reassure them that I (most of the time) considered it a positive aspect of my life. I also experienced people shouting at me from time to time as if I'd lost my hearing somehow because I was in the chair - or alternatively, talking to whoever was with me rather than to me. What frequently irked me was when shop keepers served the person with me or gave my change to them rather than me. They usually only did it once however, as I made it clear how I felt about this!

I hate being stared at by adults - children on the other hand, tend to be more frank and to **gaze** with curiosity - I quickly learned the difference between the two, and my responses to each are different. When encountering some of those adult reactions I would (depending on my energy levels) either ignore or directly confront the behaviour by asking someone if there is a reason for their staring. I'm always careful to name their behaviour, because if it angers me, then I am clear about why I am angry.

When walking using my crutches or walking stick, people are much more intrusive in some respects - that often asked question of "What have you done to yourself?" is, depending on the context and tone in which it is asked, received as either a caring enquiry, or the bane of my life. I have become quite astute at recognising the difference between the two, and my responses are different for each.

I have at times experienced overt prejudice - although I have not had to face being verbally taunted or experienced physical violence as others have. I think because I am so direct, this has been useful in preventing problems for me, but there have been times when I have felt very vulnerable and unsafe even so. I'm also a very fun loving person, so I tend to use humour while getting a serious message across, particularly through drawing cartoons. This doesn't always take away the shock or the hurt I feel however when I have been confronted by prejudice.

It is easier for me to identify and confront obvious prejudice than the more subtle behaviours that I encounter. Just prior to being diagnosed with MS, I applied for a job in a large city hospital. Because the application form had a section on health problems, I completed the form twice - once under my maiden name (when I **didn't** have a neurological disease) and once under my current name (where I disclosed that I had a neurological condition currently under investigation). Every other detail was the same, except that my 'Maiden name' application had a friend's address on it. My maiden name application got an

interview, while my current name application received a very pleasant letter advising that due to the high calibre of applicants... thanks, but no thanks. I rang the contact number, and advised that I did not want their interview and why. The woman I spoke to became very defensive when I pointed out to her that the only difference between the two applications was the neurological problem, and that I believed they were being discriminatory.

Another occasion occurred when a colleague and I were out of town and decided to have lunch together in a cafe. She was served and sat down to wait for me. The staff then served two other people, at which point I asked to be served (politely, but loudly enough for others to hear). They continued to serve the other customers, following which one served a third person while the other leaned over the counter and, in a very arrogant tone, sneered, "Yes?" at me.

I was furious. I was also very near to tears as I couldn't believe what was happening. I eyeballed her, and again in a loud voice said I was not prepared to waste my money in an establishment that treated impaired people so appallingly. The girl at the counter raised an eyebrow, and said "Whatever", then walked away. I left the place shaking. My colleague got up and demanded her money back as she was not prepared to accept their behaviour either. When she came outside, she found me bawling. She told me she too was appalled at what she had seen.

As soon as I had composed myself, I went back into the shop and demanded to see the manager. I told her my problem, and asked for her name, and the contact details of the management of the mall as I intended laying a complaint. Twice she tried to minimise the incident. However, when I also asked her for the contact details of the chain she'd purchased her franchise from, she became agitated, wanting to know why I wanted that information. I told her I also intended to inform them of this incident and to make suggestions to them about ensuring their franchise operators had adequate training around disability issues. It was then, and only then that she apologised - then tried bargaining with me that it wasn't necessary to take things that far. I wasn't interested in hearing anything more at that stage, I got the information I wanted, and left.

The subtle behaviours of others are more difficult to detect and address. Often I am only aware of their presence by a sense of discomfort or unease in a situation. When being offered help for example, I can tell the difference between a genuine offer of assistance and one which arises out of pity or distaste only by how the encounter leaves me feeling. Jenny Morris wrote an amazing chapter on help and anger (*Pride Against Prejudice*, 1991). When I read this, I was able to better reflect back on times when offers of help from some (male and female) have left me feeling angry and impotent, while from others (similarly of either gender), I had felt empowered and supported. Morris' work has often provided me with answers to the subtleties of prejudice, and I feel greatly indebted to her for this.

These (sometimes daily) problematic interactions are wearing, and can really undermine my sense of worth and well being. Fortunately I experience almost as many positive approaches which combine with my own stubbornness and sense of humour to make most days reasonable. But there have been days when I have come home, cried, and never wanted to go out in the community again. We shouldn't have to face the negativity our impairment seems to attract from others in the community - within a community that genuinely celebrates difference, these sorts of responses would not be accepted or acceptable.

As a Woman with Multiple Sclerosis:

I think that women with MS **do** have different experiences to men. I think that while I have been protected somewhat by my strong sense of self, my humour, my education and access to an alternative viewpoint on disability, my experiences reflected (at first) a very definite push to 'go home, keep quiet and out of sight, to sit down and shut up'. When I didn't, enormous pressure was put on me (particularly within my workplace) to **make** me do as I was told. Knowing the way my former manager and supervisor worked, I was sure they wouldn't treat a male staff member in the way they treated me - this was in fact evidenced when a male staff member went on a lengthy period of sick leave. Apart from griping about his absence, none of the pressure or monitoring I experienced occurred for him - but then, he didn't have an **incurable** disease.

Often people seem shocked that I take an active role in the management of my disease as well as remaining active in my community. Some of the older members of my family have a 'doctor knows best' attitude to the medical profession, and struggle with my questioning of it - one great-aunt, advised in serious tones that it "wasn't really ladylike" to do so. They also at times struggle with my continuing to work and study - their attitude is that I should accept gracefully having a dependent role. These attitudes to me reflect their socialisation - and that is the socialisation of patriarchy. We therefore agree to disagree, and they remain embarrassed I think, by my attitudes and behaviour.

My Mum and my brother on the other hand, have encouraged me to make my own decisions, although my Mum worries and at times fusses about my decision making. She does the same to my brother though, so at least she's consistent - and it's not just because I have MS! I was never socialised by my mother to be a traditional 'little girl'. For that I am eternally grateful, as it has stood me in good stead for the trials and tribulations of the disease and people's reactions to the disease and my impairment. She has always encouraged me to try what I felt was best for me, and that has continued. I think that as a result of this, combined with my own thinking and my own politics, I have been able to continue to live an independent life which happens to include caregivers, a medical team, medication and assistance to reach my goals.

My belief is that the experience of MS is different for men with MS. I believe they are socialised in different ways to have different attitudes to illness, dependence on others and to their bodies. The comparison I tend to make has been that of myself and Graeme Sinclair, from TV3. We were diagnosed with

MS within weeks of each other, and we both experienced rapid declines as our diseases followed similar courses. I read with interest how he was supported by his employer to continue with his work, and his own determination to keep up with his "Gone Fishin" outdoors programme - at the same time, I was being discouraged at every turn by my employer from getting out and doing my job. Sinclair's struggles against this 'tragedy' were seen as heroic while my efforts were viewed as unrealistic. As a well paid television presenter he could have afforded treatment with Interferon, while I depended on charity to provide me with the only remaining option to slow down my disease - he chose not to try it, I felt I had no choices left - the important point here is that he had a true **choice**.

I think that in terms of what the disease does to us, MS is indifferent to men and women (with the exception to this being that the disease tends to remain in remission during pregnancy, and the risk of exacerbation rises in the three months following giving birth). In so far as how we experience the disease, I think we are qualitatively different. I think that if men are under pressure to remain workers, breadwinners, outdoors types, then managing impairment may be far more difficult for them. But I also think that they may be encouraged more to set goals and achieve them, to question the medical people involved with them, to not 'sit down and shut up', but to set and attain their goals.

From the day I was told by my former manager to "be realistic" about my goals, I think I first experienced the very real oppression of disability (differentiated from physical impairment(s) caused by the disease). Multiple Sclerosis has given me some hard lessons, but even tougher have been those meted out by people like her.

APPENDIX IV: GLOSSARY OF MEDICAL TERMS

ACTH (Adrenocorticotrophic hormone) - a hormone either synthetically made or extracted from the pituitary glands of animals. ACTH stimulates the adrenal glands to release glucocorticoid hormones which reduce swelling and inflammation and may reduce the duration of MS exacerbations.

Acute Having a rapid onset, generally followed by recovery - as opposed to **Chronic** which is usually applied to a disease which shows worsening symptoms or is of long duration.

Aetiology The study of all factors that may be involved in the development of a disease.

Autoimmune disease A disease in which the body's immune system mistakenly attacks healthy cells, organs or tissues in the body, causing illness.

Bipolar Disorder A major mental illness characterised by periods of mania, depression and/or mixed mood. One or other phase may be predominant at any given time, one phase may appear alternatively with the other, or elements of both phases may be present simultaneously.

Bladder Dysfunction Failure of the bladder to function normally. There are three main types of bladder dysfunction seen in MS - **Storage Dysfunction** in which the bladder can not store urine as it normally would; **Emptying Dysfunction** where the bladder fails to empty fully and **Combined Dysfunction** in which the bladder may not store urine adequately and fail to completely empty.

Cell biology The science that deals with the structures, living processes and functions of living cells.

Central Nervous System (CNS) The part of the nervous system that consists of the brain, optic nerves and spinal cord.

Cognition Functions carried out by the brain which includes comprehension, speech, visual perception, calculation ability, attention, memory and executive functions such as planning, problem solving and self-monitoring.

Cognitive Dysfunction/ Cognitive Impairment Changes in cognitive function caused by trauma or disease.

Comorbidity Two or more coexisting medical conditions or unrelated disease processes.

Computerised Axial Tomography (CAT Scan) A computer integrates X-ray scanned 'slices' of an organ being examined into a cross-sectional picture.

Constipation A condition in which bowel movements happen less frequently than normal for a particular person, or the bowel movement is small, hard, and difficult or painful to pass.

Contracture(s) A permanent shortening of muscles and tendons adjacent to a joint, which can result from severe, untreated spasticity and which interferes with normal movement around the affected joint. If left untreated, the joint may become frozen into a bent position.

Depression A mood disturbance characterised by feelings of sadness, despair and discouragement. A Clinical depression can also include sleep and appetite disturbances, lack of motivation and loss of enjoyment in normal activities, and lasts for longer than two weeks.

Demyelination A loss of myelin in the white matter of the CNS.

Diagnosis Identification of a disease or condition by a scientific evaluation of physical signs, symptoms, history, laboratory test results and procedures.

Endocrine System A network of ductless glands and other structures that secrete hormones directly into the bloodstream, affecting the function of specific target organs

Epidemiology The study of the determinants of disease events in populations.

Epilepsy A group of neurological disorders characterised by recurrent episodes of convulsive seizures, sensory disturbances, abnormal behaviour, loss of consciousness, or all of these. Common to all types of epilepsy is an uncontrolled electrical discharge from the nerve cells of the cerebral cortex.

Evoked Potential Evoked Potentials are recordings of the nervous system's electrical response to the stimulation of specific sensory pathways (often sight, hearing and general sensory). In tests of evoked potentials, a computer measures a person's response times and compares these to the normal range. Demyelination results in a slowing of response times. Evoked Potentials can demonstrate lesions along specific nerve pathways, whether or not the lesions are causing symptoms.

Exacerbation (MS) The appearance of new symptoms, or a sudden increase of old symptoms, lasting at least 24 hours, usually associated with inflammation and demyelination in the brain or spinal cord. Also called an attack, relapse, flare-up or worsening.

Fatigue An overwhelming sense of exhaustion or loss of strength or endurance which persists regardless of sleep or rest.

Genetic(s) The study of inherited traits.

Hysterical Paralysis (Conversion Disorder) A loss of movement or muscular weakness that is caused by hysteria rather than an identifiable organic defect.

Immune System A complex system of various types of cells that protects the body against disease - producing organisms and foreign invaders.

Immunology The study of the reaction of tissues of the immune system of the body to antigenic stimulation.

Incontinence The inability to control the passage of urine or bowel movements.

Infection The invasion of the body by micro-organisms that cause disease.

Inflammation A tissue's immunological response to injury, characterised by the production and mobilisation of white blood cells and antibodies, swelling and fluid accumulation.

Lumbar Puncture A diagnostic procedure that uses a hollow needle to penetrate the spinal canal at the level of the third-fourth or fourth-fifth lumbar vertebrae to remove cerebrospinal fluid for testing and analysis. This procedure is used to examine the cerebrospinal fluid for changes in composition that are characteristic of MS.

Magnetic Resonance Imaging (MRI) A diagnostic procedure which produces visual images of different body parts without the use of X-rays. This is done using a high frequency electro-magnetic impulse inside a strong magnetic field which can produce pictures of parts of the body. MRI makes it possible to visualise and count MS lesions in the white matter of the brain and spinal cord in approximately 95% of patients with MS.

Metabolic Pertaining to **Metabolism** - the aggregate of all chemical processes that take place in living organisms, resulting in growth, generation of energy, elimination of wastes and other bodily functions.

Misdiagnosis To incorrectly diagnose a disease or condition.

Mobility Capability for movement.

Myelin A soft white coating of nerve fibres in the CNS which is made up of fats and protein. Myelin serves as insulation and as an aid to efficient nerve fiber conduction. When myelin is damaged in MS, nerve fibre conduction is faulty or absent.

Nerve(s) A nerve is a bundle of nerve fibres (axons) which transmit nerve impulses either away from the brain and spinal cord to the body (efferent nerves) or from the body towards the brain and spinal cord (afferent nerves).

Neurological Pertaining to the nervous system - the CNS and the peripheral nervous system which consists of nerves throughout the body.

Obesity Excessive heaviness in an individual, who is generally considered to be medically obese if he or she is 20% above the desirable body weight for the person's age, sex, height and body build.

Occupational Therapy Occupational Therapy relates to functioning in activities of everyday living, including, bathing, dressing, grooming, meal preparation, writing and driving that are essential for independent living. An Occupational Therapist assesses such functions in an individual and addresses issues such as fatigue management, upper body strength, movement and co-ordination, adaptations to the home and work environment, wheelchair assessment and seating and the use of strategies for impairments in thinking, sensation or vision.

Optic Neuritis Inflammation or demyelination of the optic (vision) nerve with transient or permanent impairment of vision and at times, pain.

Orthotic(s) Also called **Orthosis**, a mechanical appliance such as a leg brace or splint that is specifically designed to control, correct or compensate for impaired limb function. Such appliances are made by an **Orthotist**.

Paralysis Inability to move part of the body.

Paraparesis A weakness but not total paralysis of the legs.

Paraplegia Paralysis of the legs

Paresis Partial or incomplete paralysis of a part of the body.

Physical / Physiotherapy Therapy undertaken by a **Physiotherapist** to evaluate and improve movement and function of the body, with particular attention to physical mobility, balance, posture, fatigue and pain. This may include education, exercise programmes and the use of mobility aids and adaptive equipment to enhance mobility and energy conservation.

Plaques An area of inflamed or demyelinated CNS tissue.

Pneumonia An acute inflammation of the lungs caused by bacteria, viruses, rickettsiae and fungi.

Pressure Area / Pressure sore Also called a **Decubitus Ulcer**, a pressure sore results from prolonged pressure and lack of movement which occurs most frequently in areas where the bone lies directly under the skin and has little protection from muscle or fat. Pressure sores therefore most often occur on the elbows, hips, or tailbone. A pressure sore can rapidly become infected and lead to general worsening of a person's health.

Prognosis Prediction of the future course of a disease.

Psychiatric Illness Any disturbance of emotional equilibrium, manifested by maladaptive behaviour and impaired functioning, caused by genetic, physical, chemical, biological, psychological or social and cultural factors.

Remission A lessening in the severity of symptoms or their temporary disappearance during the course of the illness.

Sclerosis Hardening or scarring of tissue. In MS, sclerosis is the body's replacement of lost myelin around CNS nerve cells with scar tissue.

Sensation Related to bodily sensations such as touch, pain, temperature, acceleration and position in space

Spasm An involuntary muscle contraction of sudden onset.

Spasticity Abnormal increase in muscle tone, manifested in a spring-like resistance to moving or being moved.

Steroids Any of a large number of hormonal substances with a similar basic chemical structure, produced mainly in the adrenal cortex, or synthetically produced for treatment of a variety of medical conditions.

Symptoms Subjectively perceived problems or complaints reported by a patient. **Signs** are objectively observable physical problems or abnormalities identified by a medical practitioner during an examination.

Vascular Pertaining to blood vessels.

Virology The study of viruses and viral diseases.

Virus / Viral A minute micro-organism that replicates within the cells of a living host, generally causing disease.

Weakness Lacking physical strength, energy or vigour.

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