

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**‘You Live Too Far Out’**

**The Impact of the Health Reforms  
on Disabled Rural Women**

**A thesis presented in partial fulfilment of  
the requirements for the degree of**

**Master of Philosophy  
in  
Women’s Studies**

**at Massey University, Palmerston North  
New Zealand**

**Susan Mellsopp  
2005**

## **Abstract**

This thesis examines the impact of New Zealand's health reforms, implemented since the election of the Fourth Labour Government in 1984, on the lives and experiences of disabled rural women.

Six disabled rural women who had ongoing contact with the health system were interviewed using a research method based on feminist qualitative interview principles. The nature of the participants' disabilities necessitated that interviews were variously conducted in person, by telephone and by email. The interviews focused around their disability, their relationship with the health system during the reform period, and their experiences as disabled rural women.

Research data was divided into seven main findings. These highlighted the disjuncture between the intention of the health documents and the health related experiences of the participants. The

findings were: relevance of the health reforms; assumptions about disability; accessing disability support services; needs assessments; attitudes/gatekeeping of service providers; the rural aspect; and support networks.

Using a comparative analysis I compared the aims, priorities and objectives of the health reforms against the literature reviews and interview transcripts. Subject positions, processes and participant experiences produced the following findings for analysis: assumptions about disability; policy language; economic concerns; medicine and disability; disability support services; rural health; and gender issues.

This thesis concludes by offering recommendations at several levels to ensure disabled rural women do not continue to receive the treatment from the health system that the participants in this research experienced.

## **Acknowledgements**

I would like to thank my supervisors, Dr Jenny Coleman and Professor Robyn Munford. Your time and support has been generous: by email, telephone, and in person during supervision sessions. The positive commentary, critical appraisals and guidance I received from you both has enabled me to complete this research. Your encouragement and kindness allowed me to continue despite the personal setbacks and challenges which have occurred during the researching and writing of this thesis.

Thank you also to Dr Martin Sullivan for his continued guidance and support. Our discussions challenged me as we shared our thoughts and ideas on disability.

To the staff at Massey University Disability Support Services, the Extramural Students Society and the Massey University Library I offer my

gratitude. You have ensured the completion of this thesis through practical support in the form of equipment, photocopying in large print and emotional support.

To Dr David Worsley, your initial reservations at my undertaking a Masters Degree have been overtaken by your encouragement and friendship. Using your skills and determination to save my sight has allowed me to continue with academic study; this has been truly appreciated.

To my twin grandchildren, Daniel and Jocelyn, your birth during the writing of this thesis was extraordinary and very distracting. Your smiles make every hour spent with you rather than at the computer a joy.

Thank you to the staff of the Royal New Zealand Foundation of the Blind and Guide Dog Services. Your kind, realistic, sensible, and ongoing support has been truly appreciated.

Chocolat, my beautiful chocolate labrador, you kept me company and chewed the cover of the occasional library book. You enriched my life during the two years it has taken me to complete this research.

Finally, to the participants in this research, thank you for coming forward, without you this thesis could not have been possible. You supported and befriended me and shared your incredibly difficult and painful lives with me. I stand in awe of you, this is your story.

Due to the font size used for this thesis I have experienced some difficulties with the formatting and spacing of lines and words. I apologise for any inconvenience this may cause readers.

# Table of Contents

<b>Abstract</b> .....	i
<b>Acknowledgements</b> .....	iii
<b>Table of Contents</b> .....	viii
<b>Preface</b> .....	xii
<b>Introduction</b> .....	1
The Context of the Research .....	1
Definitions .....	3
Format of the Thesis .....	9
<b>Chapter One</b>	
<b>The New Zealand Health Reforms</b>	
<b>1984-2004</b> .....	11
The Fourth Labour Government	
1984-1990.....	12
The Business Roundtable .....	20
The National Government 1990-1996 .....	22
Delivering Core Services to the Disabled...	25
Mixed Member Proportional	
Representation National/New Zealand	
First Coalition .....	32

New Direction: The Labour/Alliance Coalition 1999-2002 .....	39
Labour/Progressive Coalition 2002- .....	48
Rural Health Policy .....	51
Disability Support Services .....	52
Recent Developments .....	53
Conclusion .....	54
<b>Chapter Two-Disabled Women: The Rural Enigma .....</b>	<b>56</b>
Overview of the Disability Literature ...	57
The Medical Model of Disability .....	59
The Social Model of Disability .....	62
Illness Versus Disability .....	65
Other Issues .....	67
Feminist Literature .....	73
Poststructuralist Approaches to Disability .....	75
Identity and Disabled Women .....	78
Difference and Other .....	82
The Disabled Body .....	86
Invisibility and Marginalisation .....	90

Dependency and the Double Disadvantage .....	91
The Rural Enigma .....	94
Disabled Rural Women .....	100
Conclusion .....	101
<b>Chapter Three-Research Methods .....</b>	<b>103</b>
Ideas Influencing My Research Method ..	103
Recruitment of Participants .....	107
The Participants .....	112
The Interviews .....	114
Ethics .....	120
Data Analysis .....	125
Reflections on the Research Method ...	128
Conclusion .....	131
<b>Chapter Four</b>	
<b>The Research Findings .....</b>	<b>132</b>
Relevance of the Health Reforms .....	132
Assumptions About Disability .....	137
Accessing Disability Support Services ...	140
Needs Assessments .....	144

Attitudes/Gatekeeping of Service Providers .....	150
The Rural Aspect .....	161
Support Networks .....	166
Conclusion .....	169
<b>Chapter Five</b>	
<b>Analysis of the Findings.....</b>	<b>171</b>
Assumptions About Disability .....	172
Policy Language .....	175
Economic Concerns .....	187
Medicine and Disability .....	193
Disability Support Services .....	198
Rural Health .....	204
Gender Issues .....	210
Conclusion .....	215
<b>Conclusions and Recommendations ....</b>	<b>217</b>
Conclusions .....	217
Recommendations .....	225
Assumptions About Disability .....	225
Medical Model of Disability .....	226
Health Policy .....	227

Disability Support Service Failures .....	229
Rural Communities .....	231
Information Dissemination .....	232
Reflections on the Research Process .....	234
<b>Appendices .....</b>	<b>239</b>
<b>Bibliography .....</b>	<b>257</b>

## Preface

I begin with my story, the personal reasons for undertaking this research. I am visually impaired and live with deteriorating eyesight. I was diagnosed in the early 1990's with macular degeneration, a diagnosis which has since been modified to bilateral degenerative myopia. Tearing of my retina and the development of a macular hole caused by severe myopia has meant the gradual loss of vision in my left eye, distorted sight, and decreased peripheral vision. The early stages of this degeneration have begun in my right eye.

I recently had surgery in an attempt to repair a rare and complex retinal detachment. This has been followed by laser surgery to prevent the retina re-detaching, but it has destroyed all my central vision. Surgery will be ongoing as a cataract develops and will have to be removed.

The grief and depression I experienced on diagnosis went unnoticed, the demands of family and a dairy farm taking precedence. Unlike the participants in this research I was able to afford private medical care, yet initially little support was forthcoming from my family, ophthalmologist, optometrist or general practitioner.

Increased impairment brought disability, dependency, loneliness, social isolation, depression, and at times despair. Initial approaches to the Royal New Zealand Foundation of the Blind brought minimal support and service provision. I was ineligible for other support services including home help.

I identify as a disabled rural woman. I have resided in rural New Zealand for most of my life, but during the writing of this thesis I relocated to a major city. I have been amazed and astonished at the services available to disabled urban women.

I believed my experiences were not unique. As they defined my life I began to consider they may also have defined the lives of other disabled rural women. A tantalising comment from a member of the Foundation's staff, who said that her visually impaired rural clients were the most disabled she cared for, was the impetus for beginning this research.

## **Introduction**

The purpose of this thesis is to examine the impact of New Zealand's extensive health reforms since 1984 on the lives of a specific and invisible group of health consumers, disabled rural women. Informed by feminist research principles and methods I will compare the aims of the health policies with participant experiences. My intention is to discover whether the medical profession and other sectors of the New Zealand health system offer an accessible, equitable and quality service to women who experience disability living in rural communities.

### **The Context of the Research**

My own impairment and the disabling consequences of living in rural New Zealand are the starting point for this research. My invisibility in my own community led me to believe, as noted in the Preface, that my experience was probably not unique. Living with the effects of the economic and health restructuring over the previous two

decades has changed my life and that of other rural women significantly.

Disability research has offered me the opportunity, similar to Morris (1991, 1992), to validate my own thoughts and feelings. It has also enabled me to make a stand against the consequences of both impairment and disability in women's lives. Like Foucault:

every time I have tried to do a piece of theoretical work it has been on the basis of elements of my own experience, always in connection with processes I saw unfolding around me. It was always because I thought I identified cracks, silent tremors, and dysfunctions in things I saw, institutions I was dealing with, or my relations with others, that I set out to do a piece of work, and each time was partly a fragment of autobiography (Faubion, 2002:458).

I have also been influenced by the writing of Barton (1996), Lunn (1997), Morris (1991, 1992) and Munford (1995) who have identified a gap in the theoretical and political knowledge of disabled women. Munford (1995:32) describes this gap as

‘silent spaces’. This research aims to ‘explore the silences’ of the disability/rural/gender context and to examine the discourses which allow this to create:

the space for an absent subject, and an absent experience, that is to be filled with the presence and spoken experience of actual women speaking of and in the actualities of their everyday worlds (Smith, 1988:107).

While in the process of writing the final chapters of this thesis I had discussions with people in government who worked in the health and disability sector regarding the information I had gathered from the interviews. They were incredulous that the experiences of my participants could possibly be happening in rural New Zealand.

### **Definitions**

Several concepts and areas of context require specific definitions and interpretation for the purposes of this research. Oliver (1990, 1996) suggests several reasons why definitions are important. These range from the historic to the economic impact of providing services for disabled

people. As we have moved forward from the word “handicap” the fundamental principles of all disability research have been based around definitions.

### *Impairment*

Beatson (2004) discusses the importance of precise and all encompassing definitions to distinguish between impairment and disability. They must reflect the distinction between the biological state and the social identity. Oliver (1996:22) defines impairment as ‘lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body’. Feminist author Wendell (1996:13) disagrees with the universalising nature of the United Nations definitions, yet still prefers their definition of impairment which is ‘any loss or abnormality of psychological, physiological, or anatomical structure or function’. For the specific purposes of this research I have chosen the definition adopted by Beatson (2004:22) which is:

an impairment is a bodily or psychological loss or abnormality which may cause

suffering and which makes it difficult, dangerous or impossible to perform tasks, to participate in community life and to play social roles in the ways taken for granted by non-impaired people.

### *Disability*

There has been extensive discussion and controversy surrounding the definition of disability. Disability politics and advocacy have debated the introduction of a positive terminology to align with new models and paradigms. Oliver (1996:5) suggests there are three distinctive elements which must be considered when defining disability: the presence of impairment; externally imposed restrictions; and self identification as disabled. Thomas (1999a:60) provides a social relational definition of disability, seeing it as:

a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being.

I have chosen the definition provided by Beatson (2004:41) which is comprehensive and encompasses the concerns raised by Thomas (1999a), the research question, and the context of this research. For the purposes of this research, a disability

is a disadvantage experienced by a person as the result of the interaction between a real or alleged, permanent or intermittent impairment on the one hand, and physical barriers, institutional structures, social policies and cultural attitudes on the other.

### ***Disabled Women***

Sullivan (1999) examines the confusion and inconsistencies in the debate surrounding the generic terms 'people with disabilities' and 'disabled people'. He believes the term 'people with disabilities' is medically based and locates disability as an individual problem. He argues that the debate lacks intellectual input and is compounded by post-modern thought with its concentration on the subjective, ambiguous and complex. Recruitment of health personnel into the

disability sector has added to the confusion. Sullivan believes that, if we accept the social model of disability which exposes the imposition of disabling structures and attitudes, the term 'disabled people' is more appropriate. For these reasons I have decided to use the terms 'disabled people' and 'disabled women' for this thesis.

### ***Disabled Rural Women***

In accordance with the above discussion I have elected to use the term "disabled rural women" for the participants in this research. This phrase offers a succinct explanation of impairment and disability combined with the financial, social and geographical aspects of rural New Zealand. It also reflects the clear sense of relationships, behavioural norms, attitudes and the values of self suffering, self reliance, independence and stoicism of rural communities (Strasser, 1999).

## ***Rural***

Defining rural has been problematic. It has no single meaning but geography and demography are usually the key determinants. Areas outside of a city or town are considered rural by most public and private groups. The term has not been used consistently which makes it difficult to apply research data to outcomes and structures such as health or education. The Ministry of Health uses the Statistics New Zealand (Official Website: 2003) definition of rural which is ‘not designated as urban, that is less than 10,000 people’. I have used this definition to provide a cultural understanding of “rural” and to set the parameters for the recruitment of research participants.

## ***Health Service Definitions***

Definitions of terms and services provided within the context of the health reforms, for example disability support services, are sourced from *The New Zealand Public Health and Disability Act 2000* (7-12).

## **Format of the Thesis**

The remainder of this thesis is structured in five chapters followed by conclusions and recommendations. Chapter One outlines the New Zealand health reforms over the period 1984-2004 within the context of the political changes and social reforms that occurred over these two decades. Chapter Two reviews New Zealand, general and feminist disability literature relating to the medical and social models of disability, illness versus disability, the disabled identity, the disabled body, difference, othering, invisibility and dependency. The chapter concludes by focusing on literature about the rural context and disabled rural women. Chapter Three outlines the methodology for this project, ideas which influenced the method, participant recruitment, and includes a brief biographical description of the participants. It describes the interview techniques used, ethical issues, methods of data analysis and a reflection on the research methodology. Chapter Four summarises the interview data. The findings are

divided into seven themes: relevance of the health reforms; assumptions about disability; accessing disability support services; needs assessments; attitudes/gatekeeping of service providers; the rural aspect; and support networks. Chapter Five compares and analyses the content of the health reform documents with the interview data and literature reviews. Seven major contrasting subject positions are presented for analysis: assumptions about disability; policy language; economic concerns; medicine and disability; disability support services; rural health; and gender issues. The key findings of this research are addressed in the conclusions and recommendations section.