'You Live Too Far Out'

The Impact of the Health Reforms on Disabled Rural Women

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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.

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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.

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.

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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

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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.

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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

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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.

Chapter One

The New Zealand Health Reforms 1984-2004

The New Zealand health system has undergone many reforms and changes during the last two decades. These have occurred alongside complex political, social and economic reforms which have restructured and transformed New Zealand, particularly its rural communities. In many instances the impact of these health reforms on disabled rural women has gone unnoticed and unrecorded.

This chapter is a chronological overview of selected key health policy documents, government reports, papers and strategies, and also includes a report commissioned by private interests into the health system. The aims, goals and objectives of the documents are reviewed with a critical focus on disability, gender, and the rural aspect.

A timeline of the key health documents and the major changes to the health system are included in Appendices 1 and 2.

The Fourth Labour Government 1984-1990

Prior to major restructuring and subsequent service delivery changes, the New Zealand health system was shaped by the power of the medical profession and a fragmented funding system. There was a growing unease regarding the public/private and primary/secondary system of health care. The *Social Security Act* of 1938 (New Zealand Government, 1938) had bound health care to the social security system. Discontent at entrenched hospital administration systems saw the pressure for change intensifying (Gauld, 2001:7-21).

The Labour Government elected in July 1984 began a reform process which offered a new and revolutionary approach to the economic management of New Zealand. Minister of Finance, Roger Douglas, initiated a transformation which saw government regulation

reduced, and which encouraged individual choice and a rationale to bring about private and corporate competition. Inherent in this was recognition that the health system had undergone only minor changes and was well overdue for both public and private scrutiny.

Reform of the health system had begun in 1983 under a National Government with the passing of the *Area Health Boards Act* (New Zealand Government, 1983). A new system of governance was established and health and disability funding was allocated on a population basis. The Department of Health retained overall responsibility for all areas of health and disability funding.

Questions regarding the viability of this Act saw the Department of Health commissioning a major review of the health system, *Choices for Health Care: Report of the Health Benefits Review* (Health Benefits Review, 1986). Examination of the relationship between state-funded provision of health care and the social and economic goals of efficiency and equity which had

been a part of the New Zealand welfare state for almost 50 years were its terms of reference. The review team was also to recommend options for reform of the health benefits system. Submissions to the review panel highlighted a powerful male-dominated, mono-cultural health system which failed to place the needs of the consumer ahead of the medical professionals.

To raise the effectiveness of the government's role in health care, five possible options for change were suggested:

- *An adjusted status quo.* Subsidised health care would continue, some services would have proportional stipulated costs. People on low incomes would be subsidised by the state.

- *The state as a residual funder.* A voucher system would bring comprehensive health care services for people unable to afford the proportional costs; and those who were ineligible for compulsory private insurance.

- *The establishment of health maintenance organisations.* The current health benefit system

would be abolished, but the state would continue to meet its residual insurer role to an organisation providing both primary and secondary health care. There would be private involvement in public hospitals for efficiency gains. It was noted that this option did not meet the health care needs of rural communities who would require continued state subsidisation.

- *The state would fund, but not provide, health care contracting with the providers.* Area Health Boards would receive population-based funding to enable them to negotiate with private, voluntary and public health service providers. General practitioners would receive a basic fee complemented by a patient service fee. This would be of advantage to low income earners, and weighting the basic fee would improve access for rural residents.

- *The state would become the monopoly funder and provider of health care.* Primary and secondary care would emanate from a network of multi-disciplinary health centres. Improved geographical

access to health care and a focus on wellbeing would result.

Establishing health maintenance organisations with the state strengthing its funding role for purchased services was viewed as the most feasible option. This was consistent with decentralisation and would promote innovation and accountability. Difficulties experienced by rural and disabled people when attempting to access health and disability services were noted. A health benefit paid to all seriously disabled people, to offer choice of care and encourage providers to be innovative, was suggested.

The recommended reforms were not well received. Major resistance stemmed from opposition to the removal of the powerful gatekeeping role of medical professionals and public concern at growing surgical waiting lists (Thomson and Gauld, 2001). However, the government continued the reform process by setting up a taskforce to review international developments in health economics, and to evaluate management of

health systems. It's report, *Unshackling the Hospitals: Report of the Hospital and Related Services Taskforce* (Hospital and Related Services Taskforce, 1988) became known as the Gibbs Report. To assist them with decision making, the taskforce commissioned a report from Arthur Andersen and Company to examine and report on work practices within New Zealand hospitals. Arthur Andersen's report suggested that hospitals were inefficient, despite the fact that information on costs, services and procedures was almost non-existent.

Area Health Board systems, the Department of Health and successive governments all came in for extensive criticism in the Gibbs Report. The dual role of funding and providing health care had led to costly inefficiencies and an appalling waste of resources within the hospital system. Triumvirate management had resulted in inappropriate decision making, poor compromises, resentment, and poor productivity.

Waiting lists, long stay, community care options, and the role of the Accident Compensation Corporation (ACC) in funding health services were considered. The Gibbs Report offered radical recommendations directed primarily at dismantling the bureaucracy in the secondary health sector, hospitals and related services by setting up a new health structure.

Five recommendations were made: separating the government's funding and provision roles; the establishment of six Regional Health Authorities who would receive population based funding; services would be purchased on a negotiated contract basis from public, private and voluntary providers; a Health Commission would fund, advise and monitor the Regional Health Authorities purchasing of services; and Area Health Boards would be established to monitor efficiency and objectivity.

The Labour Government was reluctant to adopt such radical recommendations although it was intended that the changes be phased in over a five year period. Public

opinion and the ensuing debate adopted the view that there was little to suggest that the system was in need of such fundamental reforms (Gauld, 2001:67).

Combining several previous recommendations the Department of Health published another report concerning the health system, *Health: A Prescription for Change* (Department of Health, 1988). They proposed a health structure headed by the Minister of Health, the Ministry of Health, and a Health Council whose primary role was policy and decision making. Elected Area Health Boards would become progressively responsible for all health services in their regions. The Government would devolve its responsibility for primary health care funding by negotiating budgets with each Area Health Board. Access to health care would be improved by an increase in the general medical services benefit, offset by increased prescription charges. Individuals and communities would be encouraged to take part in the decision making process.

With an election looming Helen Clark became Minister of Health in 1989. Although she offered a different approach to health issues these were not to be implemented. Questioning of the status quo and a need for further fiscal stringency became more evident. Tumultuous changes undertaken by the Labour Government became a growing concern of the New Zealand voter. The National Party was returned to power in November 1990 and, influenced by the Business Roundtable and other private concerns, it began a radical health reform process.

The Business Roundtable

Believing that a business influence was required to drive change in the health system, the New Zealand Business Roundtable, a group of influential New Zealand businessmen, commissioned a secret and independent report, *Options for Healthcare in New Zealand* (Danzon and Begg, 1991). Constrained by poor data, the report highlighted a lack of competition, lack of consumer choice, and inefficient funding to meet health needs. Poor resource allocation had

brought a restrictive and rigid atmosphere which was devoid of monitoring or measurement benchmarks. Institutionalised thinking was entrenched in a system which saw the government as the monopoly public insurer working within a fixed budget.

Danzon and Begg suggested two evolutionary corporate options for change. Firstly, the funding and provision functions of Area Health Boards would be separated and corporatised. This would bring competition between public and private service providers. Secondly, consumers could opt out of the public scheme and have their tax funding assigned to a private insurer. The ultimate goal was to privatise all public hospitals. Both these options brought with them political, economic and performance risks. Danzon and Begg felt that a fully corporate health system structured to rely on private insurance would lower government costs and evolve into a mixed public/private system.

Inconsistencies in assistance and funding for disabled people was noted, along with a lack of access for rural

populations to either private hospitals or specialists, but the corporate scenario and equity discussion failed to address either of these issues.

The National Government 1990-1996

A fiscal crisis saw the incoming National Government take a radical new direction. During the election campaign the National Party stated its commitment to the Area Health Board system, following the objectives of the Gibbs report and the Health Benefits Review. However, low morale in the health services, increasing public concern, and an agenda to privatise the whole health system brought new ideas to the fore.

A ministerial taskforce was established to report on the funding and provision of health services. Its terms of reference stated it was to be developed around a model based on access, efficiency, fairness and consumer choice. Their report, *Your Health and the Public Health* (Ministry of Health, 1991), suggested changes which had never been tried anywhere else in the world (McGloughlin, 1993). Primary health care issues were

to take precedence over the hospital re-structuring which had been targeted up until that point.

The recommendations of *Your Health and the Public Health* (Ministry of Health, 1991) were:

- Area Health Boards were to be abolished, and their purchasing and provision roles separated.
- Four Regional Health Authorities (RHAs) would fund primary, secondary and disability services. These were to be purchased from the public, private and voluntary sector.
- The role of general practitioners and nurses would become more central; they would gate-keep access to some levels of care.
- Twenty three Crown Health Enterprises (CHEs) would be established to be run by government appointed Boards of Directors.
- A Public Health Commission and a Public Health Agency would be established.
- The Department of Health would become the Ministry of Health with a policy and monitoring function.

- Health Care Plans, allowing the public to take their need for core health services to the provider of their choice, would be established.

- User part-charges would be added to some hospital services for those with the ability to pay.

- Beneficiaries, the chronically ill, and those on low incomes would continue to receive free services.

- Health costs of disabled people would become the responsibility of one agency, funded separately, underpinned by consumer choice.

"Core health services" had yet to be defined, but *Your Health and the Public Health* (Ministry of Health, 1991) aimed to rectify cost shifting and the provision of inappropriate services. Unsatisfactory access to health care in rural areas was also recognised. It was hoped that Regional Health Authorities would purchase appropriate services. This would encourage small communities to set up community trust hospitals and persuade health professionals to settle in rural areas.

Little public debate or consultation occurred regarding the reforms proposed in this paper. Suggestions were implemented over a period of two years under the auspices of the *Health and Disability Services Act* of July 1993 (New Zealand Government, 1993). Gauld (2001:92) notes that implementing the reforms was undertaken at great cost, and included the purchase of private sector expertise, consultants, and management salaries.

Delivering Core Services to the Disabled

Proposed funding changes for disability services saw the government calling for submissions from the disability sector. Publication of a discussion paper, *Support for Independence* (Department of Social Welfare, Department of Health, 1992) highlighted the confusion and dissatisfaction which had developed since the publication of *Your Health and the Public Health* (Ministry of Health, 1991). This was due to the purchaser/provider split and the financial reality surrounding the delivery of disability support services.

Access difficulties often meant clients were becoming the responsibility of both the Department of Social Welfare and Area Health Boards. Resource wastage and duplication, combined with inflexible and complicated funding, meant that finding a workable solution had become urgent.

Two major options were put forward for discussion. A single agency purchaser with a ring-fenced budget would offer improved assessment procedures and a streamlined point of entry. Guidelines for the core disability support services would ensure client protection and family support. Secondly, a decision had to be made on who would fund disability support services. This could be the Department of Social Welfare, the new Regional Health Authorities, or a new agency.

Four hundred submissions were received and the discussion paper became the policy document *Support for Independence for People with Disabilities: A New Deal: A Government Statement on the Funding and*

Delivery of Health and Disability Services (Department
of Social Welfare, Department of Health, 1992). The
new policies included: disability support services
would be funded by the Regional Health Authorities;
they would negotiate contracts with service providers;
existing clients were not to be disadvantaged; the
Departments of Health and Social Welfare would offer
policy advice to ensure a smooth transition; and
consumer complaints regarding issues of access,
negative assessment procedures and availability of
disability support information were to be addressed.

National Government scrutiny of the health system
continued. Direction of reform for the next ten years
was outlined in *Advancing Health in New Zealand*
(New Zealand Government, 1995). Three key goals
were stated: to improve the health of all New
Zealanders, to put people at the centre of service
delivery, and to get the greatest amount of health and
disability support services for the dollars available.

Government commitment to an annual increase in health and disability funding through ring-fenced budgeting to meet a rising demand for services was articulated. Funding decisions were to be based on equity, timeliness, quality and professional autonomy. Purchasing agreements were to be diversified and budget holding, described as sub-purchasing, was to be introduced. Purchase of services from groups other than the Regional Health Authorities would result. The contracting process was to become more equitable, consumer focused and reflect regional differences.

Affordable access to a publicly funded quality system, through needs assessment and evidence-based service co-ordination for people with disabilities, would be introduced. Disabled people were to be at the centre of service delivery and their independence and wellbeing were to be maximised. This managed care model of service delivery would ensure that the health and disability workforce was continually updated and trained to ensure excellence.

Advancing Health in New Zealand (New Zealand Government, 1995) also addressed the issue of the potential of telemedicine for the consumer, as well as in clinical and management practices. Information technology was identified as a powerful tool of choice for education, integration and diagnosis. Expensive leading-edge technology would be located in centres of excellence. Consumer knowledge in this field had increased expectations of customised treatment and equipment support services.

Challenges to other specific service areas and innovative approaches were also a part of the ten year plan. Maori and Pacific Islander's health, mental health services, and public health issues and policies received special mention. Inequities in these areas were to be addressed through specific resource allocation.

A supplementary document, The *Health Information Strategy for the Year 2000* (Ministry of Health, 1996), suggested guidelines and strategic building blocks for the co-ordinated management of health information by

the health and disability sector. Initiatives by groups such as the Health Information Service, Consumer Health Information Focus Group, and the Purchaser Working Group were summarised.

Legislative change would be required to ensure that quality standards and security guidelines were met in the sharing of medical information. The world-wide web was a core technology which could be used to monitor, negotiate, network and provide consumer focused health information. Digital technology and broadband networks would support telemedicine and remove geographical and other access difficulties. Health and disability information systems already in place could be capitalised. Establishment of a Health Information Council would guide and support the infrastructure. Accuracy and consumer access to information was a priority.

Implementation of this strategy was to be an evolving process, led by the Ministry of Health, the Health Information Council and the Health Information

Advisory Board. Costs of information management were to be transparent by separating them from the service budget.

Public opinion in New Zealand continued to express a growing concern over the publicly-funded health system. Attempting to allay their worries, the government published a discussion document, *Health Services 1996: Facts on the Purchasing and Provision of Health and Disability Support Services* (New Zealand Government, 1995). Health gain priority areas along with primary, secondary and tertiary services were highlighted, and concerns surrounding the increase in disability support and needs-based funding were addressed.

National Government fiscal and policy arrangements were challenged. Their vision of a competitive, competent and efficient health service driven by market orientated policy was being questioned by health professionals and the public alike (Gauld, 2001:109).

In 1993 the New Zealand voter had elected to introduce the mixed member proportional representation system of government. As the first election under this new method for electing a government loomed, health policy became a major issue due to its failure to meet the needs of those who needed it the most (Walmisley and Walmisley, 1996).

Mixed Member Proportional Representation National/New Zealand First Coalition

Formation of a coalition government is one of the main features of the mixed member proportional representation system. New Zealand First held the balance of power allowing for protracted discussions with both the National and Labour parties who had equal levels of political support. New Zealand First decided to form a coalition with the National Party. One of the coalition's first challenges was to reach agreement on sometimes vastly differing policy, including health. Effective decision making was being stymied by disagreement among agencies and sector

led policies which had not emanated from central government (Gauld, 2001:143).

The Coalition Agreement (New Zealand Government, 1996) continued with the general direction of previous policy, but gave little indication of any new policy guidelines. Commitment to a publicly funded not-for-profit health system remained. Overseen by the Ministry of Health, the core government funding allocation for health services, called Vote:Health, continued intact. Crown Health Enterprises were to be replaced with Regional Hospital and Community Service Providers. Improving health outcomes in rural areas and within disability support services was an ongoing commitment.

Financial viability concerns and continuation of the status quo saw the Ministry of Health issue a report entitled *Sustainable Funding Package for the Health and Disability Sector* (Ministry of Health, 1996). Failure of the four Regional Health Authorities and the twenty three Crown Health Enterprises to control costs

was identified as a major issue. Inconsistent and inappropriate policy settings along with unclear responsibilities were evidenced.

Several approaches were suggested by the Ministry: a formula, an envelope, and one-off funding. In recommending the formula approach they noted that an adjustment rate of 2 per cent per person per year was seen as the most sustainable. Accountability and guidance for funders, along with policy development, was required for this to succeed, despite Treasury disagreement with the inflation estimate.

In January 1998, following changes to the *Health and Disability Services Act* (New Zealand Government, 1993), Regional Health Authorities (RHAs) were replaced by Health Funding Authorities (HFAs). Later that year the Ministry of Health published the *Hospital Services Plan: Securing Better Hospital Services into the Future* (Ministry of Health, 1998). It promoted the objectives of timely access, safe and quality hospital services, nationwide fairness, value for money, and

acknowledging the special needs of rural and provincial communities. Integrated care initiatives and legislation affecting the health workforce were also considered paramount.

The government proposed to rank hospitals according to the complexity of the services they provided. These included health centres which were the main contact for rural and provincial patients, sub-acute units, secondary hospitals providing the majority of hospital care, and lower and higher level tertiary hospitals with a variety of specialised units. Enabling rural dwellers to access each of these levels was a priority.

Continued concerns regarding provision of health services to rural areas saw the Ministry of Health circulate a draft rural health policy document in 1998. Submissions received and community feedback became *Rural Health Policy: Meeting the Needs of Rural Communities* (Ministry of Health, 1999). Complementary to the government's overall health and disability policies, this document focused on providing

basic services to rural residents. Increased funding for child health and disabled rural children, along with rural mental health services, was suggested. Access to hospital services, travel assistance, and an acute management framework were seen as essential. Primary care and community health centres were an appropriate funding target. 'Rural health and disability support' was to mean appropriate front line care. Access to emergency services and the use of telemedicine to ensure contact with major hospitals with specialist care was important. Recruitment and retention of skilled health professionals and a dependable public hospital system were viewed as significant. Clinical education in rural health, supported by a Diploma in Primary Rural Health Care, was proposed to improve the team approach to effective health care delivery. These suggestions would be put in place in tandem with the internet, telemedicine, teleradiology, visiting specialists and home-based hospital care.

In 1999 the Ministry of Health published a précis of the Government's objectives for the health system. Aiming to offer a public understanding of the future of the health system, policy, and the role of Health Funding Authorities, *The Government's Priorities and Goals for Health and Disability Support Services 2000/01* (Ministry of Health, 1999) had twelve stated goals:

- Public certainty about access and quality
- Security of services
- Timely, equitable and nationally consistent access to elective services
- Acknowledging the special relationship between Maori and the Crown
- Decreased long standing disparities in health status
- Improved mental health
- Improved child health
- Improved disability support services
- Greater emphasis on population health approaches
- Well co-ordinated, integrated services that contribute to better health and disability outcomes

- Inter-sectoral collaboration between agencies and providers to achieve social policy objectives
- Improved capability and adaptability of the health and disability sector
- Sustainability of the publicly funded health system.

Health Funding Authorities were expected to offer governance, organisational strategy, capability, integrity, financial management and financial performance, risk management, reporting and information disclosure, and relationships with key stakeholders and subsidiary companies.

Gains from the re-configuration of the health system under the National/New Zealand First Coalition did not begin to emerge until 1999. A new maturity had developed in the balance between policy and the structure of the health system. Public confidence in the health system was still low when, following the 1999 election, a Labour/Alliance Coalition was installed as Government (Gauld, 2001:175-176).

New Direction: The Labour/Alliance Coalition 1999-2002

The newly elected Labour/Alliance Coalition Government reversed some health portfolio decisions. During the election campaign there had been concern expressed about the commercial focus on health care. Substantial changes occurred as the new Minister of Health, Annette King, and the Ministry of Health began to develop a series of strategies with a consumer orientated focus. *The New Zealand Health Strategy* (Ministry of Health, 2000) set a platform to action the strategies by identifying seven fundamental principles. These were:

- Acknowledging the relationship between Maori, the Crown and the Treaty of Waitangi
- Good health and wellbeing for all New Zealanders
- An improvement in health status for those currently disadvantaged
- Collaborative health promotion, disease and injury prevention

- Timely and equitable access to a comprehensive range of health and disability services regardless of one's ability to pay

- A high performing system in which people have confidence

- The active involvement of consumers and communities.

The Strategy also listed thirteen priority population health objectives: to reduce smoking; improve nutrition; reduce obesity; increase the level of physical activity; reduce the rate of suicides and suicide attempts; minimise harm caused by alcohol and illicit and other drug use to individuals and the community; reduce the incidence and impact of cancer; reduce the incidence and impact of cardiovascular disease; reduce the incidence and impact of diabetes; improve oral health; reduce violence in interpersonal relationships, families, schools and communities; improve the health status of people with severe mental illness; and ensure access to appropriate child health care services

including well child and family health care and immunisation.

Five service delivery areas were also to be prioritised: public health, primary health care, reducing waiting times for public hospital elective services, improving the responsiveness of mental health services, and accessible and appropriate services for people living in rural areas. The latter was focused on the young, elderly and Maori populations in rural areas, and the medical workforce. Quality and performance were to be balanced against issues of individual rights, consultation, co-ordination, and information management and technology.

Funding and structural changes proposed in *The New Zealand Health Strategy* (2000) required changes in the law. The *New Zealand Public Health and Disability Act* (New Zealand Government, 2000) provided public funding for the provision of personal health services, public health services and disability support services. District Health Boards with elected members were

established to offer integrated health services at local, regional and national levels. Consultation and discussion in the public arena, to address issues identified in *The New Zealand Health Strategy* (2000), and other proposed strategies, would occur. Under the new legislation, Health Funding Authorities were dis-established.

The new legislation also required the establishment of new publicly owned health and disability organisations which would improve health and include people with disabilities. The Minister of Health was required to develop a disability strategy and other health strategies. Pharmac, a pharmaceutical agency, was established to set policy and fund prescription drugs.

The Primary Health Care Strategy (Ministry of Health, 2001) was the first of these strategies to be developed. Its vision was to make people a part of the local primary health care services that keep them well, and for those primary health care services to focus on better health for all the population.

Six key directions were set out to achieve this vision. These were: to work within local communities and enrolled populations; to identify and remove health inequalities; to offer access to comprehensive services to improve, maintain and restore people's health; to co-ordinate care across service areas; to develop the primary health care workforce; and to continuously improve quality using good information.

Primary Health Organisations were to be established to achieve this. Funded by District Health Boards, they were expected to involve communities in their governing process and to develop an intimate knowledge of their local population, including disadvantaged groups. *The Strategy* noted that the funding formula did not take into account those living in remote areas. Uneven urban/rural distribution of the primary health care workforce would be addressed and it was acknowledged that further policy work was necessary to meet minimum levels for primary health care in rural communities.

Physical, psychological and financial barriers to accessing primary care and disability or other support services were to be removed. Co-ordinated care would be collaborative and multi-disciplinary between the primary, secondary, public health and disability sectors. Information about health care options was to be disseminated, particularly in rural areas, and support persons were required to go to those unable to travel to access their services.

The Primary Health Care Strategy (Ministry of Health, 2001) was designed to evolve over a period of five to ten years, and to stand alongside *The New Zealand Disability Strategy: Making a World of Difference: Whakanui Oranga* (Ministry of Health, 2001).

This *Strategy* was implemented through the newly established Ministry for Disability Issues and the Office for Disability Issues. The intention was for the government to take the lead in bringing inclusion for disabled people. Its vision was of a society that values the lives of disabled people and continually enhances

their full participation. Human rights, equity, diversity and policy development were the central tenets of this *Strategy*.

Fifteen objectives were underpinned by detailed action points. These objectives were to:

- Encourage and educate for a non-disabling society
- Ensure rights for disabled people
- Provide the best education for disabled people
- Provide opportunities in employment and economic development for disabled people
- Foster leadership by disabled people
- Foster an aware and responsive public service
- Create long term support systems centred on the individual
- Support quality living in the community for disabled people
- Support lifestyle choices, recreation and culture for disabled people
- Collect and use relevant information about disabled people and disability issues

- Promote participation of disabled Maori

- Promote participation of disabled Pacific peoples

- Enable disabled children and youth to lead full and active lives

- Promote participation of disabled women in order to improve their quality of life

- Value families, whanau and people providing ongoing support.

Disabled rural people were acknowledged in objective eight, where support for disabled people to continue living in rural areas by improving their access to services was suggested. The objective relating to disabled women had six action points. These were:

- Promote women's rights and provide opportunities for disabled women to achieve the same level of economic wellbeing and educational attainment as men

- Provide equitable, appropriate and welcoming access to services

- Support disabled women to live independent and secure lives in the environment and with the people of their choosing

- Ensure that criteria and considerations for the health and reproductive related treatment of disabled women are the same as for non-disabled women

- Include the perspectives of disabled women in the development of all strategies

- Ensure that the Ministry of Women's Affairs undertakes a leadership role in promoting the participation of disabled women to improve their quality of life.

Government departments were required to provide annual progress reports. The reports of 2001 and 2002 demonstrated a commitment by the government and the majority of its departments to raising an awareness of *The Strategy* and disability issues. The main focus was on infrastructure concerns and support programmes for disabled people. The fourth progress report for 2003-2004 stated a commitment by the ACC, Sport and

Recreation New Zealand and Housing New Zealand to follow the principles of *The New Zealand Disability Strategy* (Ministry of Health, 2001). No specific activity to support disabled people to live in rural areas was reported. The Ministry of Women's Affairs had recently shown an increased commitment to putting the objectives of *The Disability Strategy* into practice. Their *Action Plan for New Zealand Women* (Ministry of Women's Affairs, 2004:7) recognised the need to improve access to health services for rural women with disabilities.

Labour/Progressive Coalition 2002-

Re-election of a Labour Government in 2002 and its coalition with the Progressive Party brought little real change to health policy. Annette King retained the health portfolio and continued the changes proposed in 1999. Following the election, *Doing Better for New Zealanders: Better Health, Better Participation, Reduced Inequalities* (Ministry of Health, 2002), outlined the changes to the health system since the passing of the *New Zealand Public Health and*

Disability Act in 2000 (New Zealand Government, 2000). It described the current goals of the Ministry including a knowledge-based people-centred system, innovative risk taking, and the consolidation of long term goals.

Doing Better for New Zealanders (Ministry of Health, 2002) outlined a desire to ensure better health for all New Zealanders, the removal of health inequalities, and improved participation for disabled people. Primary Health Organisations were to promote healthy lifestyles through access to strong primary health care providers and by changing attitudes and behaviour. Barriers to quality care were noted: geography, attitude, financial, physical accessibility, and a lack of individual commitment and desire to access available services. A connected approach with a whole system response was suggested to alleviate this.

This document also described increasing tensions within the Ministry of Health, policy writers, District Health Boards and communities. These were attributed

to limited budgets, an inability to meet national consistency requirements, and widening public expectations of the health system. A community understanding about the fixed envelope of funds and the need for District Health Boards to prioritise funding of health and disability services were posited as essential.

Establishment of a database to improve access to up to date health information had not occurred within the expected time-frame. A secure, responsive information system offering access at all levels was viewed as a priority.

Implementation of *The Primary Health Care Strategy* (Ministry of Health, 2001) and innovative delivery of primary health services were expected to reduce inequalities and tensions. Individual practitioner decisions, as the central driver of cost and usage, would influence their workforce practices and bring competency to the use of new technologies.

Rural Health Policy

In recognition that many New Zealanders live in rural areas or small towns, the Ministry of Health set up a Rural Expert Advisory Group in 2001 to offer advice on implementing *The Primary Health Care Strategy* (Ministry of Health, 2001). Their paper, *Implementing the Primary Health Care Strategy in Rural New Zealand* (Rural Expert Advisory Group to the Ministry of Health, 2002), examined both the goals of *The Strategy* and its priorities. Although it suggested that the Ministry of Health undertake further research into rural health issues, it set out a context to support locally devised solutions to issues of primary health care. These included discussion regarding access and acceptable travel times to Primary Health Organisations, and the function of District Health Boards and rural trusts.

Suggestions for improved access to quality health care for rural residents included a rural index to recognise degrees of rurality and a rural primary health care premium. A high workload could be compensated for

by a rural bonus paid to general practitioners. Access to rural hospitals, ambulances and pharmacies should be more flexible. Financial constraints and access difficulties could be offset by mobile and outreach clinics and an upgraded telecommunications system.

Disability Support Services

Changes to funding for disability support organisations brought with them a need to discuss strategic directions and priorities. In 2002 the Ministry of Health published *Disability Support Services: Increasing Participation and Independence* (Ministry of Health, 2002). Priority budgeting had seen a separation of funding streams for those over and under sixty five. This was to offer a greater focus on outcomes for young people with disabilities, as well as consistency of service and policy.

Deinstitutionalisation, better inter-sectoral relationships, increased capability of the disability support services workforce, and more individual responsibility for managing one's disability were

proposed as part of the new strategic planning. Specific high need disability groups, such as people with autism spectrum disorder, were a focal point.

Recent Developments

The present Labour/Progressive Coalition Government has continued to revise and revisit the delivery of health services in New Zealand. Their most recent report, *Reducing Inequalities in Health* (Ministry of Health, 2002), sets out a framework to reduce identified inequalities. Interventionist strategies are proposed at four levels: structural, intermediary pathways, health and disability services, and impact.

District Health Boards were to take the lead in targeting underlying affective factors. These included the social and economic determinants of health, behaviour, and the environment. Disabled people, who are at risk of downward mobility, were acknowledged in this report.

Conclusion

This chapter has reviewed a selection of the key health policy documents covering the period 1984-2004. They reflect the multitude of health reforms which have occurred in quick succession and the focus on health policy changes. Reform documents have been referenced against the complex political changes which have restructured New Zealand over the last two decades.

Key objectives, visions and action points of each reform document, and the ensuing changes, have been described. Particular attention has been paid to those reform documents focused on the funding and delivery of disability support services and attitudinal change.

Attention to the specific needs of individuals based on disability, rurality and gender has been minimal. Centralisation of services, hospital closures, competitive disability support funding structures, and the reluctance by medical personnel to work in rural areas has had a severe impact on disabled rural women.

Health service opportunities offered via modern telecommunication and treatment methodologies have been proposed for over 10 years but have not been instigated.

The following chapter, Disabled Women: The Rural Enigma, will focus on the literature relevant to disabled women, particularly New Zealand publications and literature relating to disabled rural women.

Chapter Two

Disabled Women: The Rural Enigma

This chapter is a review of disability literature focusing on relevant New Zealand authors and key disability issues central to the lives of the participants in this study. From the wider field of disability literature I have selected writers who have examined issues of significance such as the models of disability, disability and health issues, the disabled identity, and disabled women.

An overview of the literature is followed by discussion on the medical and social models of disability, the illness versus disability debate, and some key issues specific to this research. The chapter then focuses on feminist literature which examines issues central to this study including poststructuralism, identity, difference, othering, the disabled body, invisibility, marginalisation and dependency. This chapter concludes by examining

the small amount of published literature on rural women and disabled rural women.

Overview of the Disability Literature

Consistent themes were evident in mainstream disability literature published during the last two decades. Disability writers such as Oliver (1990, 1996), Barton (1989, 1996, 2001) and Morris (1991, 1992, 1996, 2001) have explored issues such as definitions and the history of disability, its politics and ideologies. Oliver (1990, 1996) also evaluated the relationship between the formulation of social policy and issues such as education, health and citizenship.

Campbell and Oliver (1996) offered a comprehensive insight into the politics of the British disability movement. They concentrated on the significant issues that have empowered disabled people, political analysis, and confronted the social order which they suggested must be reformed to include disability.

The debate surrounding the subject of disability has continued to grow. *Disability and Society: Emerging Issues and Insights* (1996) and *Disability Politics & the Struggle for Change* (2001) by Barton drew together significant disability writers and researchers to discuss the social differences experienced by disabled people. Areas such as education, charities, prejudice, empowerment and justice were examined through a variety of contexts. Their analysis is extended within the New Zealand setting by Beatson (2004), who included information about the disabled body and demographic and economic principles against a background of the local culture.

Formulating models of disability was the focus point for much of the early literature. Models of disability explained how disability was constructed medically and socially, and the impact this had on the lives of disabled people. Critical thinking on the fundamentals of discrimination was important for both the political and policy approach.

The Medical Model of Disability

Experience of disability was, until the 1990s, discussed from medical and sociological perspectives. Oliver (1990) was amongst the first to focus on debate around the meanings of disability both for the purpose of official definitions and as an argument for the rights of disabled people. He believed the medical model of disability developed from the individual or personal tragedy theory. Capitalism excluded people who failed to meet its needs and requirements and this allowed the medical model to take precedence. Segregation occurred, and the disabled body became the focus and the province of the medical profession. Oliver believed this model had been adapted to allow governing jurisdiction over disabled people by both the medical profession and its allied para-professions. These pseudo medical personnel had been instrumental in the strengthened relationship between disabled people and the hospital system. This had brought a re-definition of impaired bodies

within modern rehabilitation systems. According to Oliver:

> services too 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 little or no control (1990:6)

Oliver put his original explanation of the medical model into context in *Understanding Disability* (1996) when he discussed changes in legislation, new disability organisations with a political focus, and new methods of action for change. His retrospective account analysed the medical model more subjectively, and he reached the conclusion that medicalisation was one component of an individual model of disability. He suggested that the medical profession brought a clinical diagnosis to a 'patient' and they located:

> the 'problem' of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability (ibid:32).

The origin of the medical model has continued to be the subject of much discussion. Hughes (2001:28-30) argued that the regulation of social disorder brought about the discursive construction of special populations who were bio-politically problematic. He proposed that disabled people were confined to medical spaces, were re-defined as sick, and their every move within the community was controlled by the medical profession. They had been forced to medicalise themselves in order to construct an environment that met their needs. The institutionalisation and perceived economic and social liability of disabled people allowed medical control and managed health care (Linton, 1998:50).

Thomas (1999a:145-159; 1999b:47-55) concluded that definitions of disability encouraged the medical model. Language such as 'chronic', 'static' and 'functioning' failed to notice the social disadvantages and genuine experiences of disabled people. Modern precise definitions had put the

medical model into context and brought the focus onto the individual social experience of disability.

The Social Model of Disability

Questions about the medical model and its role in the "oppression" or "personal tragedy" modelling of disability, along with the increased political and policy interventions of disability activists, saw the development of a social model. This model posits "disability" within society and its failure to provide for the needs of disabled people. Restrictions were imposed by society at several levels and included oppression, prejudice, discrimination and inaccessible buildings and transport systems. The social model considered the location of invisible and marginalised groups within the disability community.

According to Oliver (1996) this model was critical in formulating a new understanding of how disability was constructed, established a basis for disability awareness, and exposed the social

barriers which created disability. The exclusion of disabled people from many activities such as employment, education and housing was a crucial aspect of the social model.

'Mapping' the disability revolution in New Zealand, Beatson (2004:59) made the point that the social model also included the effects that nature, population, the economy, politics, welfare, community and culture had on constructing disability. He also argued that this model allowed individuals to voice their personal opinion and to initiate political activism. Beatson acknowledged this had complex implications as individuals often pursued conflicting and contradictory goals.

In her book *The Rejected Body,* Wendell (1996:35-38) compared the two models. She contended that both the biological and social interacted to create disability. She factored in what she referred to as 'the pace of life'. Taken for granted by non-disabled people, the pace of life could marginalise

and reduce participation for people who moved more slowly and had limited energy levels.

Critiquing the social model from a feminist perspective by incorporating the opinions of other disability writers, Thomas (2001:48-58) suggested it was important to remember that the personal experience of disability meant some restrictions could be attributed to the effects of the impairment and could not be causally attributed to social barriers. She argued that perhaps the gendered leadership of disabled people's movements could explain the faults of the social model. Thomas believed that a feminist engagement with the personal experience of disability had exposed the need to examine the social interaction between disability and impairment effects.

These arguments about the social model are questioned by Shakespeare and Watson (2000) who doubted the model's reliability. Breaking the link between disability and impairment and replacing it

with embodiment and impairment could remove the rhetoric around these distinctions. Their criticism extended to the model's denial of pain, and its failure to deal with multiple oppressions. Oliver (1996:42) supported this view, and he suggested a social model of impairment to stand alongside the social model of disability.

Crow (1996) advocated renewing the social model, suggesting that the implications of illness for both impairment and disability should be recognised. Re-defining impairment might achieve this, and dispensing with the medical model may allow illness, impairment and disability to be defined advantageously (Campbell and Oliver, 1996:197).

Illness Versus Disability

Debate and argument about each of the powerful disability models highlighted the conflict of understanding about the division between illness and disability. Writing early in the debate, Zola (1977) contended that those with a vested interest

in the continued existence of disability, and in the privilege of accessibility, adhered to medical rhetoric around illness.

In *Understanding Disability* Oliver (1996:33-37) argued that both the medical profession and pseudo medical professionals continued to support the perception that all disabled people were ill. Their training socialised them to believe they were the experts. Social researchers continued their attempts to classify disability and this had deepened the illness/disability divide. Oliver believed the artificial division between illness and disability hindered the acceptance and political empowerment of disabled people.

Extending his analysis, Oliver (1996) contended that the conflict was both epistemological and methodological. Supporters of the medical model believed there was a causal link, while followers of the social model perceived disability as an exclusive totality. The social model did not deny

that illness disables, but reiterated that illness could be treated medically. Illnesses could become extremely disabling but when coupled with medical interventions became oppressive.

Wendell (1996:19-22) in her feminist analysis of the body questioned the concerns over the illness/disability divide, arguing that many disabled people were extremely ill. She felt that prejudice had brought the realities of the debate to the fore.

Other Issues

Morris (1991, 1992, 1996, 2001), Oliver (1990, 1996), Thomas (1999a, 1999b) and other disability writers have drawn attention to many issues of importance for disabled people, disability politics and research. These included identity, the body, difference and othering. Their application to areas such as education, health, welfare, race or gender was critical for understanding disability.

Foucault stated that identity was constructed by external institutional discourses and self knowledge (Priestley, 1999:94). The word 'identity' signified both an individual existence and a similarity with others. Definitions and language had created an implicit need for the disabled individual to understand and confirm their identity. A personal adjustment process interacted with the progression of political, negative, positive and empowering thought (Thomas, 1999a:112-120).

'Claiming disability', with the permanence and ramifications this identity involved, also meant accepting terminologies and the dominant cultural view. Identity could be moderated to comply with expectations and levels of control, but the disabled identity had a multitude of meanings (Linton, 1998). In a recent email to a disability discussion list Shakespeare (2004) suggested the analogy between disability and gender/race/sexuality could be misleading. He stated that 'disability may be more like poverty: not an identity to be celebrated'.

In the context of discussing oppression Vernon (1998:205) stated:

> the effects of being attributed several stigmatised identities are often multiplied (exacerbated) and they can be experienced simultaneously and singularly depending on the context.

Vernon also considered that stigma played a crucial role as an individual formulated their disabled identity. Experiencing discrimination and oppression could lead to them rejecting an identity predicated upon disability.

In her book *Disability, Self and Society* (2003) Titchkosky, who is dyslexic and has a blind husband, wrote 'everyone, disabled or not, who interacts with disability is engaged in producing its meaning and social identity' (ibid:4). She argued that disability acted upon and expressed itself in mainstream life within connotations of normality. She found this both perplexing and thought provoking (ibid:4,38). She also suggested that the

disabled identity is not specifically owned by those who identify themselves as disabled people.

The role of the medical profession in formulating the disabled identity is discussed by Morris (1991), Swain and Cameron (1999) and Weedon (1999). They all adopted the position that medicine exercised a powerful role by default. This power was transferred to other disability professionals who perceived the disabled identity as resting on medical treatment, rehabilitation and psychological adjustment.

Disabled people moderated their identity within the restrictions imposed by the notion of difference. According to Morris (1991:15-38) and Wendell (1996), disability 'difference' was socially constructed as a negative concept reflecting prejudice and discrimination. Wendell believed this prejudice resulted from physical difference rather than physical limitations. She argued for the possibility of pride in being different as it could

reduce stigma and desensitise people to their difference. In her discussion on genetic selection she questioned whether valuing disability as difference was the result of social rather than medical implications. This view was supported by Oliver (1996:89) who felt that integration based on difference was a politically achievable reality.

Discourses of disability allowed the negative process of "othering" to occur. Wendell (1996:60-61) explained this by suggesting there were two essential processes which designated someone as 'other'. Firstly, people were grouped together as the objects rather than the subjects of experience, and secondly, they were seen as symbolic of something else, usually something to be rejected and feared. The symbolism inherent in illness and disability therefore contributed to the othering of disabled people. Munford and Sanders (1999:81), in their research on families, stated that once a person is labelled as 'other' significant personal

negotiation and mediation were necessary for positive identity formation.

Munford (1992, 1995) has also written extensively about the disabled body. She made the statement that we must first see the normative aspects of the body before we can understand its role in reinforcing the disabled/non-disabled dichotomy. The effects of this were elaborated in Munford and Sullivan (1997:24):

> the expectation to ignore or deny the materiality of the disabled body means that its 'abnormalities' and deficiencies are simultaneously minimised and emphasised, with the effect of both marginalising and excluding the disabled subject as other.

Other disability writers have analysed the role of the body in the construction of disability and the disabled identity. Corker and Shakespeare (2001), Sherry and Chenoweth (2000), Sullivan (1996) and Weedon (1999) concluded that the disabled body was the subject of powerful oppositional discourses imposed by the medical profession. They

interpreted the body in a multiplicity of ways and defined and classified it. The medical meta-narrative allowed no space for the exploration of variations.

Feminist Literature

Feminist literature published since the 1970s has focused on the establishment and analysis of theoretical positions such as liberal, radical and psychoanalytic feminisms. These were used to analyse the position of women in society and to bring change and equality for women in many sectors. As the body of feminist literature grew writers focused on political and social issues such as sexuality, employment, class, race, welfare, housing and health. Male disability writers with a personal experience of disability, such as Oliver and Shakespeare, had included brief discussions about disabled women in their work. Their analyses were usually included in discussions about race or gender.

Women's experience of disability received little attention from feminism until the publication of *Pride Against Prejudice* by Morris in 1991. Moving away from more traditional feminist methods, Morris used her personal experience of disability to underpin the importance of prejudice, dependency, care-giving, and the prospect of effecting change politically. This provided the catalyst for other disabled women to write their subjective experiences into both narratives and academic research. The naming of women's experience within social analysis was important for establishing an understanding about disabled women's lives.

The *personal is political* slogan brought increased engagement by feminist writers with disability. Morris (1996) and Thomas (1999a, 1999b) agreed that the previous failure to address important aspects of disabled women's lives may have contributed to the reproduction of disablist ideas and attitudes. Thomas (2001) concluded that

feminist epistemologies had now been widely applied to disability politics and research. This had not been without its tensions as many agendas had a masculine priority (Morris, 1991, Thomas, 1999a).

Poststructuralist Approaches to Disability

"Breaking the silence" about disabled women proved difficult within standard feminist theoretical methods of analysis with their emphasis on race, gender and sexuality. Post-structuralism offered a language/discourse analysis applicable to the deconstruction of identity, difference, the body and other concepts of importance to disabled women. It rejected traditional assumptions about truth and reality, and concentrated on the subjective elements of oppression and crucial aspects of feminist politics.

Discourses constituted knowledge about social practice as well as the nature, body, mind and emotions of those they governed. Foucault believed

the discursive construction of women's bodies was central to re-constituting the social norm of femininity (Weedon, 1997:104-105).

According to Sunderland (2004) the fundamentals of gendered discourse were not always visible, and their identification was always interpretative. Discourses were a social and constitutive process and when they were deconstructed all theoretical positions could identify and challenge them. Lather (1991) and Tong (1989) disputed this, suggesting that post-structuralism was a stand alone theoretical position which could transcend the limitations imposed by other feminisms. They argued it could break silences and include the marginalised through both speaking and writing.

Fairclough (1995, 2001) explained that language and discourse analysis could clarify power relations within an international and global frame. He also noted that the development of the internet had reduced power inequalities and allowed networking

which offered new possibilities for social and political mobilisation.

Gendering Disability (Smith and Hutchison, 2004), a post-modern collection of papers presented at the Gender and Disability Studies Conference at Rutgers University in 2001, addressed how disability intersected with social, cultural, historical, artistic and citizenship issues. Papers on gender and disability, the disabled identity, and emerging disabilities such as post-polio syndrome were included. Smith (2004:4) concluded that the disabled identity was plastic, and disabled people were often seen as too embodied or frail to be a real presence.

Writing critically about disability issues, Fine and Asch (1988) and Morris (1991, 1992, 1996) have subjectively explored issues such as relationships, ethnicity, care-giving, abortion, employment, sexuality and reproductive rights. It had also been highlighted by writers such as Corker and French

(1999), Hekman (1999), Linton (1998), Lunn (1997) and Morris (1991, 1996) that there were issues which were of particular importance to disabled women. This review of the literature now examines those issues.

Identity and Disabled Women

Women who become disabled lose their previous identity and have to take on the mantle of a new one. Feminist theories of identity were developed initially from psychoanalysis. Humm (1995) defined a woman's identity as multiple and self-contradictory. Feelings of rolelessness experienced by disabled women emanated from their dual status of being both disabled and female. Accepting the label 'disabled' meant choosing an identity which had negative implications. Gender assigned roles were denied and became the site of struggle, stress, and social disadvantage. The disabled identity could remove a woman's individuality and also contradict significant sexual expectations (Keith, 1996; Wicks, 1998).

Lunn's doctoral thesis (1997) has been important in providing an understanding of what identity means for disabled women, its negative connotations as well as its empowering characteristics. She discovered resistance to an enforced identity based on disability as an inferior concept. Several of her research participants felt it was their own attitude which established their identities. Lunn concluded that the disabled identity was a viable political construct, a spectrum which could be crossed for the formation of a new identity. She argued that disabled women should make decisions about the definitions and distinctions involved and work to resist labelling, alienation, subversion and negative discourses. They should be challenged to craft themselves a new identity and resist the power inherent in the label which advocated personal and public loss.

Wendell (1996:26) also made the point that 'accepting disability means a deep change of identity'. Concurring with other disabled women

writers such as Morris (1991, 1992, 1996) Thomas (1999a) and Wicks (1991, 1998), Wendell explained that the disabled identity was unstable and required constant evaluation, and was only one portion of the self. She related how she often compared herself with women she saw as more disabled than she was.

Disability must always be understood in terms of its complex and sometimes tenuous relationship with identity. Arguing for the seamless configuration of the cultural narrative of disability with the academic narrative, Linton (1998) believed that the academic inquiry into disability could set aside its medicalisation and bring a truly inclusive society which would ultimately disrupt the social order. Hekman (1999) contradicted this viewpoint in her book *Feminism, Identity and Difference*. She concluded that the question of identity had sidetracked feminist thought and raised intractable problems which would see identity removed from the feminist political agenda.

Wicks (1998), in her thesis on disabled older women, proposed that disabled women's identity was linked to the double disadvantage. While this has been questioned by Beatson and Perry (2002), Wicks also argued for the concept of border identities; the multiple voices present within marginalised groups.

Contributors to the global examination of identity, *Women, Disability and Identity* edited by Hans and Patri (2003), agreed that disabled women experienced multiple disadvantages: being women, disabled, and women with disabilities. Their identity became a minority status constructed through symbols and values that conferred an outsider status.

Discussing the marginalisation of disabled women, Munford (1995) argued for challenging the social frameworks which excluded their identity. She made the point that crossing the personal/political spectrum could allow disabled women to establish

a new status and identity. Peters (1996) supported this view, noting that when facing disability many women felt a sense of 'twoness' when their self centred identity was intertwined with their disability.

Difference and Other

Implicit in literature about the disabled identity is an understanding that it required "difference" or being conveyed as "other" to exist. Both terms had been used previously to understand patriarchy, biological and sexual biases, and ideologies of abnormality, inferiority, powerlessness and subordination. According to Humm (1995:64) the concept of difference was developed originally by feminism to explain the polarity between men and women. It was adapted to show that women's voice is different, and could be categorised negatively to include the subordination and exclusion of women.

Thomas (1999a:104-112) and Weedon (1997, 1999), who used the term 'differently different'

both agreed that it was a key political concept which had recently been adopted by all marginalised groups of women. Thomas argued that social construction theory could explain the concept of difference sufficiently. She believed it did not allow for a biological concept to be included. Thomas also questioned Morris's assumption that a woman's disability was her key point of difference.

"Normality" was a concept which could be balanced against disability. Morris (1991) maintained that social reactions to physical difference allowed the processes of exclusion and negation to occur. The non-disabled world assumed that normality was the aspiration of all disabled women. Linton (1998:22-25) believed that the use of *abnormal* and *normal* in discussion moved discourse to a higher level of abstraction which increased ambiguity and misunderstandings. These words had the power to affect an individual's worth

and acceptability, and could determine social position and society's responses.

Attempting to re-define difference, Wendell (1996:57-84) proposed that biological difference underlay both the essentialist and social construction of difference. Wendell believed difference could be viewed as a pre-cursor for cure, becoming obscured within categorising and political analysis.

According to Dignani (2003:129-136) and Hans (2003:34) gendered difference was exclusionary, isolating and restrictive. Negative connotations reflected both deprivation and the denial of emotions. For Dignani and Hans, difference was a dominant international social pattern.

Difference could also have positive connotations. Acknowledging difference could be liberating for disabled women and reinforce their stand against isolation and silence. When difference was

celebrated it would lead to a disruption of medical oppression (Munford, 1995; Munford and Sullivan, 1997; Weedon, 1999).

Understanding the imposition of difference on disabled women could help to comprehend how they have been labelled as "other". Non-disabled women would feel threatened by disability and assign it to a different group and gender. This idea was developed by Simone de Beauvoir in *The Second Sex* (1953) to explain why women were seen as negative and inessential. Otherness had now come to represent being outside the accepted conceptual system. Discourse and attitude played a negative role when the concept of other was applied to disabled women. Grouping them together symbolised both fear and rejection. Disabled women also contributed to the process of 'othering' within the disabled community when they place emphasis on the most dominant disabled group (Beatson, 2000:341; Georgeson, 2003:91;

Humm, 1995:197; Sherry and Chenoweth, 2000; Thomas, 1999a; Wendell, 1996:61).

Lunn (1997) discussed her role as a researcher in the othering process. She conceded that New Zealand's culture normalised discourses which enabled othering to occur, and discourses of the feminine produced a subject position about the body which further alienated disabled women.

The Disabled Body

Differences in bodily construction conferred a complex and distinctive focus on the bodies of disabled women. Their bodies were culturally reproduced and were determined by physical, social, political and economic discourses. Commentators such as Lunn (1997), Munford (1992, 1995), Tremain (2001) and Weedon (1997, 1999) suggested that a disabled woman's body was still biologically and emotionally defined by male values and norms.

Munford (1992:14) argued that disabled women were constantly being assessed against the material expectations which surrounded the female body. They may be observed and examined and then subjected to all kinds of behaviours that function to determine how the body should behave. Munford (1995:38-43) also concluded that we must not deny the painful bodily experience because the body is also a site of struggle.

The body was the place where the health system asserted its control and its social authority reinforced and classified it (Sullivan, 1996). The medical community was committed to technology and intervention to correct the deviant body. Emphasis on cure does not tolerate human vulnerabilities, and disabled women were viewed as medically abnormal (Garland-Thomson, 2004; Wendell, 1996).

According to Frank (1988:43) and Thomas (1999a:137), medical and professional discourses dominated and controlled the body, overlying

socially constructed ideas about the body. This brought the disabled body into conflict with the role of rehabilitators.

Dyck (1998) traced the implications imposed by the diseased body on feminist geography. Discussing women's experience of multiple sclerosis, she showed how their responses to diagnosis and the physical manifestations of the illness were linked to struggles around identity and relations of power within the medical system. She questioned the notion of objectivity, the de-centring of the medical model, and how 'space and place' brought diversity to the experience of both disability and women.

Frank (1988) explained the formation of realistic body images and concluded that society had embodied women with expectations of physical beauty and sexual marketability. Supporting Frank, Wendell (1996:85-116) criticised the role of the media in the cultural acceptance of the ideal body.

She believed this led disabled women to strive for bodies they could not attain. Less than perfect bodies were also seen as lacking femininity.

Several authors have adopted Foucault's theory of Bio Power to analyse the discourses which impact upon the body. Lunn (1997) Sullivan (1996) and Tremain (2001) argued that multi-directional power and knowledge controlled an individual's body. Sullivan explained that bio-power directed docility and the way the body was used. He made the point in his discussion on the paralysed body that individuals had difficulty letting go, of making sense of their changed body image. It elicited fear, dread and embarrassment.

There has been little discussion in feminist literature on positive aspects of the disabled body. Lonsdale (1990) and Munford (1995:43) pointed out that a positive outlook could bring transformation, celebration and rejoicing. Incorporating a strong self image could be

particularly difficult for the newly disabled to grasp.

Invisibility and Marginalisation

Examination of the literature showed some recent attention had been paid to the invisibility and marginalisation of disabled women. Hans (2003:23) described disabled women as living behind a curtain of invisibility. This curtain could be self imposed and include physical, emotional and attitudinal perspectives.

Feminist authors had approached this theme from a variety of theoretical perspectives. Morris (1991, 1996) and Thomas (1999a, 1999b) had utilised the social construction model to examine the role that impairment, disability, attitude and structure play in marginalising disabled women. Their position was supported by Titchkosky (2003:231) who stated that disability was an experience of marginality, a position from which alternative ways and possibilities of being were developed.

Disabled New Zealand feminist writer Wicks (1991) adopted the position that invisibility was caused by dynamic and discriminatory interactions within sectors such as employment and education. She concluded that appropriate policy formulation would uncover invisible lives. Munford's paper (1995) on this subject suggested that various discourses had been used to maintain the silence of disabled women, leading to societal ambivalence. She examined the role discrimination played in invisibility, and how the exploration of personal lives could disperse the silences. Her paper concluded with a discussion on the role social policy language played in marginalising disabled women, noting that a greater understanding of how disability is constructed could bring greater visibility.

Dependency and the Double Disadvantage

Two other issues raised in the feminist literature have a particular relevance for the current research: dependency and the double disadvantage.

Dependency had been discussed in both a positive and a contradictory manner. Disabled women were seen as passive, docile and dependent. Barton (1989:17) said:

> dependency is created amongst disabled people....because their lives are shaped by a variety of economic, social and political forces which produces this dependency.

Morris (1991, 1996, 2001) agreed the word had both negative and positive connotations and was given specific characteristics by the non-disabled. She suggested that disability did not necessarily create dependency, that it was a part of the dynamics of domination, vulnerability and prejudice.

Medical professionals and rehabilitation experts perpetuated existing stereotypes which encouraged dependency. These originated within the confines of the medical model, and arose out of discourses within both medicalisation and segregation (Hughes, 2001; Lonsdale, 1990).

Georgeson (1994) concluded from her research into health experiences that her participants saw themselves as dependent, yet they felt that interdependence was the ideal. She found that professionals viewed independence as self care, whereas disabled women saw it as being in control of one's own life and decisions. These findings were supported by my own previous research (Mellsopp, 2001, 2002).

Dependency, invisibility and the silence of disabled women was underpinned by the concept of the double disadvantage, that of gender and disability. Beatson and Perry (2002) have contested the existence of a double disadvantage, arguing that except for socio-economic factors, disabled women achieved higher levels of education and experienced less disadvantages than disabled men. Lunn (1997) Morris (1991) and Thomas (2001) also maintained that it is not helpful to talk of double disadvantage; they felt it was a negative

concept which could further victimise disabled women.

In contrast, Traustadottir (1990) expressed little doubt about the existence of the double disadvantage. A failure by the feminist movement to acknowledge disabled women, and their inability to fulfil expected roles, had aligned disadvantage with personal tragedy theory. This argument was expanded by Lloyd (1992) into issues of sexuality, attitude, challenging stereotypes, and the images of disabled women. She believed disabilities were subsumed under disadvantage and invisibility.

The Rural Enigma

Recent literature about New Zealand rural women and their changing multiple roles has been constructive, but has remained almost entirely within the domain of rural journalism, social historians and geographers. Rural publications such as *Straight Furrow* and *The Dairy Exporter* have written about the changing role of farmers wives

both on and off the farm. Other literature, both national and international, has examined the social history and development of rural communities and rural women, particularly through the eyes of their representative organisations (Shaw, 1993).

In *Contested Countryside Cultures* (Cloke and Little, 1997) which offered a geographical focus on the space of nature, rural identity and the discursive power of otherness in the British rural context, the authors questioned whether orthodox representations of rural culture had become repressive. Essays included in the book represented emerging issues such as rural lesbians, employment and rural women, the role of rurality as a signifier of identity, and the exclusion of those 'who do not belong' from rural communities. Notions of belonging and the contradictions which existed claimed tolerance and acceptance, but in reality denied difference and rejected challenges to the norms of beliefs and behaviours (Cloke and Little, 1997:277).

International and national journals with a rural perspective such as the *Journal of Rural Studies* and *Sociologia Ruralis* have published selectively on the effects that social, economic and political issues have on rural women. Several of these articles are reviewed below.

Teather (1996) investigated the social responses of farm women in Canada, Australia and New Zealand to the changes in agriculture over the last two decades, and the way rural women's organisations had responded. She reached the conclusion that the establishment of organisations which could speak for farm women at government level had countered their deep sense of marginalisation and alienation within their industry.

Wilson (1995) discussed the impact of government policy changes on the agricultural and rural community by studying a rural service town in Southland. The rural downturn was offset by the

expansion of dairying in Southland. As a result, farmer's wives had restructured their lives and income. Interviewing the residents of a small Waikato town, Chalmers and Joseph (1998) studied the effects of rural restructuring on the elderly. They found there was a need to empower people living in rural areas so they could understand the impact of two decades of change.

Other journal articles such as those of Grace and Lennie (1998), Liepens (2000), Phillips (2002) and Saugeres (2002) reflected on the rural identity within the post-modern and discursive. They believed that rural lifestyle discourses were easily identified, and the construction of masculine and feminine in rural communities allowed the male identity to take precedence. Saugeres (2002) argued that women's roles had been overtaken by machines, and they now lacked an embodied connection with the land. Grace and Lennie (1998) found a certain ambivalence by Australian rural

women to identify as feminist; they believed feminism was an urban phenomenon.

Geographers Little (1987) and Whatmore (1991) applied feminist geography to study the nature of patriarchy in rural communities. Dominant rural ideologies reinforced women's place in rural society and this was affected by remoteness and a lack of resources. Women's domestic roles were meant to compensate for their participation in other off farm work. Little and Austin (1996) researched the 'rural idyll', and noted there was a rural 'other' which maintained rural gender relations. Their paper showed how a woman's identity as a 'rural woman' was tied into general images and understandings of rural society. This 'rural idyll' was questioned recently by Panelli, Little and Kraak (2004) who offered a feminist critique of the notion of rural community. Experiences differed relative to class, gender, sexuality, age and ethnicity. Rural communities were no longer harmonious, safe and peaceful. Rural women were

becoming more fearful for their safety as rural crime increased.

Health care was very important to rural New Zealand. An analysis by Panelli and Gallagher (2004) of the survey conducted by Rural Women New Zealand in 2000-2001 into rural health care found that District Health Boards were ignoring the particular requirements of rural communities. Access to all services including maternity care, and services for the elderly and the disabled, were being eroded. Concerns about limited access included cost, distance, waiting lists, referrals, and a lack of available general practitioners. Farmers, the self employed, Maori, and those receiving a benefit were most likely to have experienced inadequate access to medical services. Respondents reported finding themselves caught between District Health Boards and the ACC over treatment costs. The survey found that a rhetoric of 'traditional family values' placed a hidden cost on rural women. The report concluded with the

recommendation that the Ministry of Health needed to recognise the inadequacy of health service access for rural populations (Panelli and Gallagher, 2004).

Disabled Rural Women

A two year search failed to uncover any literature about disabled rural women in New Zealand. Savage (1989), conducted a survey for the Disabled Persons Assembly of disabled women and their health experiences, but no rural women were invited to take part in the forums.

International literature such as *Voices of Disability* (University of Washington, 1995), a research report on access to health care for disabled people in rural America, noted the obstacles to access which still persisted, particularly for women. Reluctance to treat disabled people, inappropriate care and a lack of transport were cited as specific issues. Choice and quality of life often overrode other difficulties which were experienced.

Hans and Patri (2003) included narratives from rural India and Asia in *Women, Disability and Identity*. Bhambini (2003) discussed disabled rural women in India, suggesting they faced some unusual problems. They experienced the triple discrimination of disability, gender and economic status, and were vulnerable to neglect and abuse. Disabled rural women in India were unable to obtain employment and they became a burden on both themselves and their families. Illiteracy and a lack of information prevented them learning about their bodies and disability. Long distances to services and health facilities exacerbated their poverty and isolation.

Conclusion

This chapter has reviewed New Zealand, general, and feminist disability publications. Several issues of key importance to this study have emerged from the literature. The persistence of the medical model of disability has reinforced the impact legislation, the medical profession and the rehabilitation

process has on the lives of disabled women. Language is central to understanding the difference between illness and disability, the disabled identity, abnormal and normal, and the social control exerted by medical professionals and rehabilitation specialists over the disabled body. Disabled women are disadvantaged and marginalised but are becoming more visible in the literature, particularly that written by feminist authors.

The paucity of literature on disabled rural women supports the conclusion of Fine and Asch (1988) and Hans (2003:11-39) who suggested that a silence in the literature had obvious implications. The current research will contribute to filling that gap and reducing the invisibility of the disabled/rural/gender context.

The following chapter outlines my research methodology and includes a short biographical description of the research participants and the ethical issues which occurred.

Chapter Three
Research Methods

This chapter describes the methodologies that informed this research. It includes a discussion of feminist, disability and qualitative interview principles and their influence on my perspective as an insider. My research process is described in detail and includes a short biographical description of the participants. This chapter concludes with a reflection on ethical issues associated with my methodology.

Ideas Influencing My Research Method

My research was informed by selected feminist and disability research principles. Feminist research methodologies pay attention to the politics of knowledge production and are based on a respect for the participants. They also acknowledge the subjective role of the researcher. Drawing on my own autobiography assisted me in discovering the experiences of silenced and invisible women and

enabled me to produce knowledge that would make a difference in their lives (Acker, Barry and Esseveld, 1983; Letherby, 2003; Oakley, 1988; Reinharz, 1992).

Respect for the women I interviewed meant I had to make a decision on whether to call them respondents, participants or interviewees. Letherby (2003:32-34) makes the point that using the term 'participant' implies the offer of an unrealistic level of equality. Nevertheless, a desire to see both '*I*' as the researcher and '*they*' as the participants as equal led me to define the women who were interviewed for this research as participants.

There are unique issues involved when researching the lives of disabled women. Feminist disability research is expected to politicise, challenge fundamental assumptions, empower, emancipate, and importantly for me, be reciprocal (Reinharz, 1992). I wanted to produce knowledge *for* rather

than *about* disabled women (Harding in Letherby, 2003:46).

Like Olesen (1998:306) I felt that

> some of the most skilful work on women's subjectivity and experiences has been done in the area of women's health, in ways that unsettle...and lead to theoretical and pragmatic consequences.

Allowing the women to speak for themselves, to direct the research agenda, was also important to me, although conducting qualitative interviews can be time consuming and the research relationship can become complex. Oakley (1988) believes that the participants have to adapt to the researcher's definition of the situation. Knowledge was filtered and constructed as the balance of power shifted between the participants and myself.

Women interviewing women means they discuss topics which 'have no name' (Reinharz, 1992:23). Establishing a rapport sanctioned me to develop an

effective quality of communication and to discuss public and private issues. Self disclosure on my part encouraged reciprocity, negotiation of meanings and mutual understanding (Lather, 1991:60-61). Qualitative interviews endorsed a period of "breaking the ice" during which we discussed the weather, family, recent outings and pets.

As a rural woman with a disability I was an insider in this research. Interviewing from this perspective, rather than that of detached objectivity, made connections, rapport building and empathy easier. I received implicit messages of respect and a silent communication of a shared experience and understanding. As a researcher it offered me legitimacy, safety and validation, and meant that I persisted under often difficult circumstances to ensure the research process reached its conclusion (Letherby, 2003; Stanley and Wise, 1993).

My own assumptions and experiences as a disabled rural woman increased my awareness of the power differentials inherent in the insider position. Positioned as both an insider and an 'academic expert' by one participant produced some as yet unresolved discomfort on my part. It brought significant insight into my responsibilities as a researcher (Letherby, 2003; Naples, 2003; Tolich and Davidson, 1999; Wicks, 1998).

Recruitment of Participants

Ethical approval for this research was obtained from the Massey University Human Ethics Committee. Included with the application was a copy of the advertisement used to recruit participants, the information sheet, and a consent form. An outline of the direction the interviews would take was also part of the application. Several adjustments in wording were required before final approval to begin the research process was given.

Six disabled rural women were recruited to take part in the research. I felt this number would offer diverse opinion and experiences, different disabilities, and a balance of geography and District Health Board areas. All the participants were required to live in a rural area, to be over the age of sixteen, to have a disability, and have some form of ongoing contact with the New Zealand health system. I had to exercise a great deal of determination and persistence to find disabled rural women to interview. Several different methods of recruitment were utilised to ensure that I found sufficient participants.

Initially small, independent and free rural publications were emailed with an outline of my proposed research. I explained my need to recruit participants, and attached a copy of the advertisement approved by the Ethics Committee. These publications included *The New Zealand Farmer's Weekly, Straight Furrow, Dairyman* and *Coast and Country*. Two published a small portion

of my email in their letters to the editor section, but failed to publish the approved advertisement despite a follow up telephone call. Two women contacted me, one by telephone and one by email, after reading these publications.

Advertisements were placed on several rural and disability internet notice boards and websites including *Weka, Rural Women New Zealand* and *Not Just Gumboots and Scones*. One research participant was obtained from these websites. Several websites, including the farm discussion site allied to Fonterra, refused my request to place an advertisement. A call for participants was also placed on the *Discuss* disability mailing list which is based at Massey University. One participant was recruited via this list. Two participants were referred by social workers who had read my advertisement in various mediums.

Several subsequent advertisements did not bring any response. CCS (formerly the Crippled

Children's Society) published a notice in their newsletter about my research. I was contacted by the secretary for the Minister for Disability Issues, Ruth Dyson, to obtain my permission to insert a notice about my research and need for participants in their *Participate* email newsletter.

I approached the *Waikato Times* to ask if they would insert a small notice about my project, and my search for disabled rural women to interview, in the Tuesday farming section. This brought several unexpected consequences. A reporter came to my home and interviewed me; I then travelled to Hamilton the following day for photographs to be taken. A large article was published the following week but unfortunately my email address was spelt incorrectly. A correction was published the following day in another section of the newspaper. Several women contacted me by telephone over an extended period of time after reading the article. I placed them on a waiting list in case one of the women who had approached me initially withdrew.

Staff at The Royal New Zealand Foundation of the Blind read the article and with my permission contacted several of their rural members on my behalf. All experienced macular degeneration, were very elderly, and their lack of contact with the health system made them unsuitable participants. Several radio stations communicated with me and I was interviewed on a provincial radio station, national radio and my local community radio about my research and search for participants.

The first six women who contacted me proved to be the most appropriate and were selected as the participants. They were domiciled over a wide geographical area in both the North and South Islands. My initial definition (definitions are included in the introduction) of "rural" which was 'of the country, remote, distant and isolated, inaccessible or out in the sticks, living at least 20 kilometres from the nearest urban centre' had to be modified to 'not designated as urban, that is less

than 10,000 people' as only one participant met the original criteria.

The Participants

Jane

Jane is in her fifties, married, and lives in a small rural North Island town. She moved there eight years ago from her farm so she could receive adequate health services. Jane has motor neurone disease, uses a wheelchair, and experiences almost total muscular atrophy. She has difficulty speaking. Jane has moderate contact with the health system; she visits a specialist, accesses medical supplies and needs several daily caregivers.

Sarah

Sarah is in her fifties, is separated, and resides on a small North Island lifestyle block. She is employed within the health system. She has been disabled for six years with a gastric disorder which makes it impossible for her to eat normally. Sarah receives

health care designed to support her nutritional needs and undergoes frequent surgery.

Kiwi Mel

Kiwi Mel is in her forties, is married, and lives on a remote South Island sheep and cattle farm. Since her teenage years she has been disabled by severe rheumatoid arthritis which restricts her mobility and makes living on a farm difficult. There are few health services in her area and she travels long distances to access the specialist services she requires.

Barbara

Barbara is in her fifties, is single, and lives on a remote North Island lifestyle block. She has a rare inherited neurological disorder as well as a range of other disabilities. These restrict her mobility and her independence. She has received a range of health services, most of which have failed to meet her specific needs.

Polly

Polly is in her fifties and she lives with her partner on a lifestyle block near a small North Island town. She has multiple sclerosis, experiences many of its associated symptoms, and now uses an electric wheelchair. Polly receives excellent support from several sectors of the health system.

Sharon

Sharon is in her thirties, is single, and rents a cottage on a farm near a small North Island town. Disabled for most of her life by a genetic muscle disorder she experiences chronic pain and has been in a wheelchair since the age of 17. Sharon's contact with the health system is minimal as she is unable to access the services she requires due to a perceived remoteness by various disability support services.

The Interviews

The interview method chosen has to be appropriate for the research question (Letherby, 2003:87).

Creative and flexible interviewing techniques were required because geographical dispersion and severe disability meant that all but one of the participants were for the most part confined to their homes. Focus groups were therefore not appropriate, and face to face interviews would be difficult to embark on due to my visual impairment. Facial expressions and body language cues are important for face to face interviews and I am unable to detect these.

Audio-taped, semi-structured telephone interviews using a speaker telephone was chosen as the most appropriate method. Telephone conversations allowed for friendly and comprehensive discussion of the research question, exposure of issues I had not previously considered, and initial "breaking the ice" entrée into each interview.

A covering letter, initial questionnaire, information sheet and a consent form, to be signed and returned in an enclosed stamped addressed envelope, was

posted to each participant (see appendices). Information requested in the initial questionnaire was general such as age group, type of disability, its effect, the District Health Board area they resided in, and the level and type of support they received from the health system. Each participant was given the option of choosing their own pseudonym. Three chose to, I then assigned a pseudonym for the other three participants. Polly who can no longer write required support from her partner to fill in the initial questionnaire.

Jane emailed me to ask if her husband could be interviewed on her behalf as she could not speak well. Email correspondence with difficulties overcome by the use of special technology was possible, so I decided to conduct the interviews with Jane by email. Tolich (2001:83-85) notes that researchers do not know who is answering electronic communication and that security may be an issue. This did not become a concern with Jane's responses. Attachments were not used, the

questions and answers were written in the body of the email. I sent Jane approximately 10 questions in each email and, when she answered these and returned the email, I expanded on her replies, added new questions, and sent her the next email.

When the consent forms and initial questionnaires were returned appointments were made by email or telephone to begin the interviews. Telephone interviews were conducted in the evening to take advantage of reduced telephone charges. At the conclusion of the first interview a time was made for the second interview to take place. Schedules were changed on several occasions for a variety of reasons which extended the interview period.

Interviews took place from mid December 2003 to late January 2004. Barbara and Sharon were interviewed on three separate occasions for approximately an hour. Kiwi Mel was interviewed twice, each interview also taking approximately one hour. I listened to the participants' first

interview tapes before conducting their following interviews. This ensured that no particular aspect was omitted. Kiwi Mel's second interview reflected the rural aspect of this research. Telephone calls at the arranged time were not answered and I phoned repeatedly for over an hour. She had been delayed on the farm helping her husband move sheep.

Polly's first interview was conducted by telephone, the second was face to face in my motel room when I attended a friend's wedding in a nearby town. Sarah, who lived in close proximity to me, requested a face to face interview and chose to come to my home for the day. These two face to face interviews did not present the difficulties which were originally anticipated. Jane's email interviews were conducted over a two month period.

Initial questionnaire data had provided information with which to begin the open-ended but guided and

semi-structured interview process. I prepared a list of themes and topics to be covered, with general questions about the participants' experience of disability beginning the discussion. Reinharz (1992:24-25) explains that a guided interview requires attentiveness on the part of the researcher, and trust that the participant will lead the interviewer in a fruitful direction. She continues by making clear the necessity of some fixed response questions to prevent digression. I found that one question easily led to another and that listening and hearing became very important (Acker, Barry and Esseveld, 1983:432). Drawing participants back to the issue in question was sometimes difficult. Questions examined the themes of gender, rural, and contact and experiences with all sectors of the health system.

When concluding the final interview I offered the participants the opportunity to make suggestions on ways the health system could be improved to meet their particular needs. These suggestions will be

included in the final chapter. Follow-up questions were administered by email, both for clarification of issues and for opinions on topics raised by other participants.

Ethics

Several ethical challenges were presented during the research process. Patai (1991:150) says that 'in an unethical world we cannot do truly ethical research'. Researchers do experience moral dilemmas when they intrude on the lives of other people and I found my own values, beliefs and prejudices presented themselves. This was particularly evident when I was faced with a level of pathos and misdirected anger that I had difficulty agreeing with. Telephone discussions with my supervisors alleviated my concerns.

Anonymity was a key consideration of my ethics application, yet it was difficult to retain when recruitment had come from a small population. One participant became aware that her sister had

contacted me as a result of the article in the *Waikato Times.* Another expressed considerable concern about being identified, while the other five felt that if their identities became known at some stage it could bring increased support for the issues surrounding their own disability.

Research informed by feminist principles can still reproduce inequalities the researcher is trying to reveal and transform. We observe that the participants get something out of it too, but fail to note that *other* people are always the subject of *our* research (Patai, 1991:149). I was aware that on the completion of the interviews I was free to leave with the data having intervened in private lives and their intersection with the health system. This could have allowed my participants to be exposed and vulnerable to the whims of disability service providers, health professionals and general support networks. This was a fear that several of the participants expressed, and my research findings and analysis chapters have reflected this.

Relationships based on my integrity and participant trust and confidence were important. My representations of these women's lives and consciousness had to be valid. As suggested by Lather (1991:65-68), I used catalytic validity which represents the degree to which the research process focuses and energises participants' towards knowing reality in order to transform it. This enabled me to focus on the intentions, attitudes and values of both myself and the participants.

Letherby (2003:129) and Oakley (1988:44-46) argue that the research relationship is not a friendship. They suggest that a real friendship may develop once the research process is completed. During the course of the interviews the researcher/participant relationship remained intact. One participant expressed an interest in enrolling for university study and I was able to explain to her how to go about this. Another referred me to equipment for the visually impaired that I was unaware of. I have since developed an ongoing

friendship with one participant. We email each other frequently and "talk" about the weather, our children and grandchildren, social outings and life's frustrations.

Media attention and the radio interviews which followed the publication of the article in the *Waikato Times* were mainly positive, but also resulted in some dubious offers of assistance. I received a proposal of sponsorship from a public relations firm. Initial contact by telephone from a member of their staff led to an understanding that I was to provide a list of the practical and financial support I thought appropriate. I requested paper, printer cartridges and the printing of chapters of my thesis for correction. My suggestions were approved via email, but, when enquiring how I would access their support, it was stated that a 'misunderstanding' had occurred. The only support available was an offer to read drafts of my chapters. Reluctantly I emailed a draft of the introduction to my contact with the firm who

proceeded to mark it, changing and correcting statements which were accurate. I declined to continue further with the sponsorship.

Immediately after my interview on national radio, I was approached by a television producer wishing to discuss the possibility of making a documentary based around my research. Ethical requirements of anonymity and confidentiality would make this difficult, and I am still considering the implications of this.

Researcher and participant risk was seen as negligible when the ethics application was lodged. The interview process proved otherwise. Open ended interview techniques ensured the participants safety, but I became very distressed by comments made by several of the participants. Treatment they described having received from several levels of the health system was extremely upsetting for me. My reactions required a telephone debriefing session with my supervisors.

Data Analysis

I listened to the interview tapes, and using a counter on my tape recorder, noted the position of relevant data. I then began what became an unexpectedly extended process of transcribing the data onto a password protected computer file. Several of the tapes required extensive editing as participants had used extraneous words such as 'um' repeatedly, or began a sentence, stopped, and changed direction with the beginning of a new sentence. Email interviews had been printed out and placed in a locked cupboard as each set of answers was returned. The brevity of some of the answers made it simple to extract significant data.

One participant had taken the opportunity to vent her anger at a variety of government departments and other organisations not directly related to the research question. A large portion of her interview tapes subsequently proved unusable. I posted her a transcript of the quotes I intended using from her interviews and she modified many of her

statements. She also refused permission for several quotes to be used in writing up my research findings. This participant stated that she had now obtained part time employment in a government department and did not want to put this at risk. Revision of her statements in favour of a powerful institutional discourse has almost silenced this participant's voice in my research findings.

Transcripts of the tapes were printed out to enable me to read them and extract the dominant themes and differences. I used a set of coloured sticky markers, one colour per theme, to locate the relevant data on the printed transcripts. This, as well as the size of the printed transcripts, helped with my visual difficulties. I identified the following 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. I selected themes and data which gave an overall view of the impact

of the health reforms, and quotes which supported these.

Several methods of analysing the interview data were considered, including a discourse analysis. My choice of method had to consider the research question, the qualitative and subjective nature of the data, and what was absent from the discussion. The rich interview material and the findings I had identified during the transcription process showed there were few points of divergence and many of difference between the health reform documents and the participants' experiences.

Using a comparative analysis I matched the aims, priorities and objectives of the health reforms against the literature reviews and the interview transcripts. I extracted quotes I identified as being most representative of the specific comparative findings. Subject positions, processes and experiences in common formed the themes for analysis.

In agreeing with Letherby (2003:118), who suggests we should acknowledge our intellectual privilege in our editing and written representation of interview data, I was careful not to over generalise subjective accounts. I selected those quotes which best represented the words and experiences of the participants. Names of places, District Health Boards and institutions were left out or changed. Due to some unanticipated personal circumstances accepted procedures regarding the forwarding of transcripts of quotes to participants had to be modified. I emailed each participant with an explanation, and, except for the one mentioned above, all understood and accepted the changed procedure saying they trusted me.

Reflections on the Research Method

I believe that being an insider had a major influence on my research method and design. Although I remain a "friendly stranger" to five of the women I interviewed, the shared experience of being a "kindred spirit" was a privilege. I was

always aware that I was undertaking a unique piece of research and would identify with the participants in their own personal and political journeys. Insider status at times masked my ability to both interview and analyse. Initially, I simply did not see the uniqueness of the rich data I had obtained, my own experiences veiled them.

When embarking on this research I was unaware of the difficulties I would experience recruiting participants. I do not believe that disabled rural women are the small population who replied to my wide advertising, and now consider that to identify as such is extremely difficult. Women who responded were mostly a very strong, assertive group of women who all wished to use this research to make a difference in their lives and the lives of others.

I believe that the feminist informed interview method chosen was the best approach given both my own disability and the severe disabilities of the

participants. Although I undertook a pilot interview with a friend, it did not prepare me for the need to structure the interviews in a way which would prevent some of them becoming too long for women who tire easily. The subjective and guided nature of the interview meant that while each participant was not always asked the same questions each theme was covered in depth from their perspective and their individual experiences.

Letherby (2003:115) states that the researcher does not always hold the balance of power in the relationship. My identity as a women's studies researcher did not appear problematic for any of the participants, but their perception of me as an academic disability researcher seemed to offer them powerful expectations that I could not meet. Several of the participants believed I could effect change at a level they had been unable to achieve themselves. One participant constantly asked if she was answering the questions correctly, if she was

'ok', and appeared to see me as somewhat more than equal.

Ethical issues which arose could not have been avoided. They were unexpected and continue to play a role in this research. I did not consider making my supervisors aware of several issues which had arisen in my own life. Doing so may have allowed them to prepare me for the effect discussing similar difficult issues could have on me when conducting the interviews.

Conclusion

This chapter has described my research method, the recruitment of participants, my interview process, and has outlined the problems that I encountered. It has also examined the ethical issues which arose as I conducted this research. The next chapter summarises my research findings from the interview data by describing the participants' experiences of the health system and its impact on their lives.

Chapter Four
The Research Findings

Chapter Four presents the data collected from the interviews with six disabled rural women. It explores the women's experiences of the health reforms on their disabilities. Sharp contrast between the intentions of two decades of health reforms and the women's experiences of the New Zealand health system was evidenced. Policy had not been followed by action in the lives of five participants.

The data was analysed and seven themes emerged: 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.

Relevance of the Health Reforms

Overwhelming frustration with the health system, particularly disability support services, was evident during the interviews. In part this was related to the

participants' limited knowledge about health services and disability organisations, but it also presented as an inability to access information or health care of an acceptable level. The health system was viewed as the domain of government, policy makers and self seeking hospital bureaucracies. Sarah summed up this view in her comment 'by the time it trickles down to us it means absolutely nothing'.

Throughout the interviews there were numerous accounts of misunderstandings and erroneous assumptions on the part of health professionals, and an inability for disabled individuals to relay their needs successfully to carers and medical staff. Living in a rural area compounded these issues. This was despite the express intention of *The New Zealand Disability Strategy* (2001) to support a disabled person's decision to reside in a rural community.

A common theme was the lack of information made available to disabled people, despite *The Primary Health Care Strategy* (2001) requiring detailed

information about health care options to be widely disseminated. Consumer access to health knowledge had been a priority since *Advancing Health in New Zealand* (1995) outlined the reform process for the following decade.

All the participants were sceptical that the needs of rural health consumers were considered in health policies. They felt a wider range of services, such as mobile outreach clinics, had been offered in the past. Jane suggested this was before reforms and strategies which 'use all the right words' were implemented. Barbara commented that disabled people who wrote or implemented policies and strategies were fortunate in having gained employment, and stressed that they should extend their knowledge of various disabilities and their effects on rural women. There was a general belief that these people had little concern for disabled women who resided in rural areas and were unable to work.

Commenting on *The New Zealand Disability Strategy* (2001), one participant felt it was just a mission statement. She believed it was not being implemented because initially no one was aware of what it would cost. When asked about *The New Zealand Health Strategy* (2000) Sarah, a nurse whose work required her to apply the varying strategies, explained:

> I'm only a nurse, do you know how much we don't know, we know nothing. I'm afraid we just tossed it because it means nothing to the coal face workers. They don't put forward ideas for implementing their ideas. It's written in such PC language.

The current policy emphasis on promoting wellness and wellbeing was seen as detrimental to the needs of disabled people. 'Disability is permanent' stated Sharon who believed that a wider focus on disability, alternative treatments, and gender specific long term health and support needs would be more appropriate.

Systems of health care administered by District Health Boards were intensely criticised. When questioned about their local District Health Boards all the participants commented on the bureaucracy involved

and the constant changes in management and structure. Sharon said:

> it's disjointed. I don't think the patients are actually thought of. It's the best comedy show out, they should be had up under the Trade Descriptions Act, they really should because it's just a load of baloney.

There was an overall sentiment that competition for funding meant health providers had no interest in ensuring up-to-date efficient quality care was provided in rural areas. Kiwi Mel summarised the feelings of the participants saying: 'they couldn't care less. It would be nice to think they actually thought something of us'.

Extensive explanation and clarification was required of New Zealand's health and disability systems during the interview process. Participants had a general awareness there were organisations dedicated to health and disability issues, but they could not name the majority of them. Sarah was contemplating contacting the office of the Health and Disability Commissioner to report ongoing incidences of horizontal violence in her workplace. She had read a pamphlet about this service.

Other health and disability organisations such as the Office of Disability Issues, Primary Health Organisations, Workbridge and Mainstream Employment were, in the main, unknown to the participants.

Assumptions About Disability

The New Zealand Health Strategy (2000) and *The New Zealand Disability Strategy* (2001) made specific reference to the role attitude played in further disabling New Zealanders and stated that:

> more often than not, barriers are made out of people's ignorance towards something different. Attitudes have been identified...as the major barrier that operates at all levels of daily life.... attitudes and ignorance make their presence felt as stigma, prejudice and discrimination. ....Sometimes the combination of attitudes and behaviours can seem to create almost insurmountable barriers...whole systems or organisations can become a barrier (The New Zealand Disability Strategy, 2001:6).

Assumptions expressed by members of the health and private sector towards disabled people, which Sharon summed up by saying: 'you are not a valued member

of society' reflected a poor awareness of disability issues. Negative attitudes had victimised the women at some level of their health care. They believed attitude was their main disability, making them feel unvalued and at times depressed. Sharon explained:

> they actually make you feel like a piece of dirt to be honest, that you're not worth anything. They only focus on the negatives of your situation.

Descriptions of 'crawling' to doctors who 'think they are God', and 'putting on a brave face' to other medical staff and disability service providers reinforced this. Sarah said:

> it would be nice to be able to say something without having to lift up my shirt and show them my abdominal scars.

Sharon and Barbara felt women on a benefit were often treated with indifference by health care professionals. Sharon also believed that some health service providers had a need to make disabled women who received a benefit feel bad about themselves. She had been told that she should be supporting herself and should not be getting a benefit.

Attitudes the participants projected toward their own disability were important. According to Sarah:

> you get very angry with the woe is me, then the attitudes of others that fight all odds to survive. I have fought, I think that is the only reason I am alive.

When asked directly if being a woman made any difference to the way they were treated by health professionals all the participants said no, they felt men would receive the same treatment. However, Kiwi Mel subsequently spoke of male patients being given preference by the receptionist at the orthopaedic clinic, and recounted several other experiences which had made her angry. Polly commented: 'being a woman, it's harder I think because some people think you're trying to seek attention, but you're not, far from it'.

The participants' experiences of the assumptions and attitudes expressed by general practitioners and specialists, disability service providers, occupational therapists, physiotherapists and particularly clerical staff are discussed later in this chapter.

Accessing Disability Support Services

The *New Zealand Public Health and Disability Act* (2000) provided for publicly funded health and disability support services. These services were designed to promote the inclusion, participation and independence of people with disabilities. Disability support services were complex and crafted to meet individual needs. They were community based and delivered by private not- for-profit organisations such as the IHC and CCS (*Disability Support Services: Increasing Participation and Independence*, 2002).

Policy and contracting changes which began following the health reforms of 1993 meant other agencies took on roles previously provided by hospital based agencies. The ACC and Work and Income New Zealand (WINZ) also funded some disability support services. Barbara, who felt the system for accessing support was 'terrible' commented:

> I am not ACC so I have missed out on help and rehabilitation, although ACC is not necessarily all that good either now.

Support services were wide ranging and could include: needs assessments, home based care, personal care, household management, respite care, day and vocational services, equipment provision and rehabilitation services.

Once eligibility of access was established three interlinked processes took place. Firstly, a needs assessment identified and prioritised a person's care and support needs. Secondly, a funding based plan to co-ordinate and identify the most appropriate options available for the client was written. Clients were informed that some services were means tested and there may be a waiting list for others. Thirdly, services were provided in the form of an individual support package. Polly, who had experienced no difficulty obtaining services, said:

> it was very easy, if you pass the criteria it was very easy. They came along and said: 'what do you want done and what can you do'? I said there was nothing I could do so they said 'that's fine'. There was no assessment as such once I wanted it and I needed it. The services started as soon as I wanted them so that wasn't a problem, that was good.

The Ministry of Health funded community based agencies and advisory services to disseminate disability information as a key tool to enable disabled people to access a wide range of disability support. However, accessing knowledge about the existence of appropriate support services and methods of contact was often difficult. In Jane's words:

> the only problem with these services is knowing of their existence and where to get hold of them. I've just stumbled onto some of them. That's why it's so important to join the support groups.

Living in a rural area made it more difficult to make contact with disability support organisations. Jane suggested 'the district nurses should be more aware of what is available' while Sarah believed 'there is really not much to access'. Often a lack of empathy meant their needs were not seen as genuine. Sharon, who had been disabled since her teenage years, received no support until she was injured several years ago. She commented that fear of rejection, 'they look at you like oh my gosh, it's crawled out from underneath a rock', meant she initially lacked the courage to request care and support services. All the participants felt living in

an urban area would make access to help much easier as it would probably be offered to them. Kiwi Mel was emphatic that service provision varied greatly between the North and South Islands. Kiwi Mel, Polly and Jane commented that spending time in hospital meant their needs were recognised and they obtained necessary assistance.

General practitioners were usually the initial referral point. Their lack of knowledge on how to access the disability support system and the types of services available appeared as a common theme. 'What really frustrates me is there is no grand plan. I feel really pissed off' said Barbara. All the participants wondered if there were services they might be eligible for but knew nothing about.

When asked how they had managed to obtain services initially it was usually 'just by trial and error or by sharing information' said Barbara. Sharon also stated:

> I didn't get a lot of help for many years, no one told me it was available. You find out from

someone else, from friends and other people with disabilities.

Although five of the participants had difficulty accessing appropriate health and disability support services they did eventually receive some home based assessment from a service provider.

Needs Assessments

The role of the needs assessor is to work with the client, identify their needs, and refer them to the appropriate services. This involves understanding, trust and good listening skills. They must work within the principles of *The New Zealand Health Strategy* (2000) and offer access to a comprehensive range of health and disability services regardless of one's ability to pay.

The Ministry of Health required that appropriate, quality, patient-centred services be made available to disabled people living in rural areas. This was reinforced in *The New Zealand Disability Strategy* (2001) which stated it would 'ensure that disabled

people are able to access appropriate health services within their community' (ibid:26), access to services would improve, and the criteria for consideration for disabled women would equate with that of non-disabled women (ibid:33).

The reality was quite different. Once a referral had been processed the needs assessment was not a positive experience for the participants. Home-based needs assessments only occurred following a traumatic hospital stay or by constantly following up applications made by their general practitioners. Several participants abandoned the process initially because it proved too difficult or they were expected to pay for it. Sarah, whose treatment cost her District Health Board $1000 each week, experienced extreme trauma after mistakenly receiving accounts for this. She described it as 'a double slap around the face....it's protecting some idiot working in an office'. Despite their situation usually becoming one of desperation, follow up requests from general practitioners had either been ignored or became lost in the system. Kiwi Mel

suggested you have to keep ringing, you have to 'nag for it'. Barbara believed disabled women were 'falling between the cracks'.

Four of the participants felt they had never had a real needs assessment, a process Jane described as a 'pain in the bum'. She felt it was a waste of time to have it done every year and also commented:

> The [support organisation] fieldworker put me onto [name of District Health Board] home care who first visited two weeks after my husband left. She didn't think I needed help because I lived on a farm. I didn't get any more help until I went public.

Barbara, in talking about her needs assessment, said:

> I never want to see another needs assessor in all my life….they play all sorts of little power games and are sometimes quite stupid or barely literate.

She felt needs assessors who visited her lacked a practical understanding of her individual and rural needs. They defined her reality and made assumptions about her difficult situation.

Distance was cited as the major factor in refusals by disability service providers to undertake a needs assessment. Kiwi Mel, who lived 98 kilometres from the nearest hospital, was told 'it would be difficult to get someone to come out this far'. Sharon had received a similar reply and said: 'I'm only twenty minutes out of [name of town] but you would think I was five hours from the nearest city'.

Despite difficulties initially making contact with a needs assessor, all of the participants had eventually received some disability support services. These ranged from home help to showering, other personal care and the provision of equipment. This was usually tempered by pre-conceived ideas about their rural lifestyle.

When a home help co-ordinator visited Jane who was alone on a farm with two small children, she was told 'farmers are wealthy and should pay their own way'. Despite being severely disabled for many years she had only received an adequate level of home help for the last eight or nine years. Sharon, also in a wheelchair,

was told she could have three hours of home help a week, but one hour of this would be used for travelling. Her home helper lived just fifteen minutes down the road, coming to vacuum the house and clean the bathroom once a week. This was a level of help Sharon found totally unsatisfactory.

New regulations issued by the ACC and Occupational Safety and Health (OSH) had restricted the range of duties undertaken by a home help. Caregivers were carefully monitored in tasks they undertook to prevent accidents. They could no longer take disabled women to emergency medical help if necessary; neighbours, family or friends were expected to transport them. Windows, ceilings and high cupboards were not cleaned and had to remain dirty. Extreme discomfort at the cleanliness of their homes, and feeling home care services had become too business-like to the detriment of the clients, was mentioned by all the participants.

Applications for basic equipment such as a wheelchair were often longstanding. Jane, who previously only received home help, explained:

> once I got onto the occupational therapist at the hospital....I was able to get a wheelchair and get my bathroom done.

Sharon had waited many years for a needs assessment. She received a new wheelchair and a perching chair to help with doing the dishes following the visit of an occupational therapist on exchange from overseas. She had recently had a visit from a new needs assessor from CCS and was excited about the possibility of receiving extra services in the near future.

Polly's experience was a complete contrast. An extended hospital stay both preceding and following diagnosis saw her overwhelmed by an excellent needs assessment. She continued to receive a level of care none of the other participants had experienced. Polly was supported by regular home visits from the service providers, a field officer, and an occupational therapist. Someone showered her and did all her housework. Her general practitioner advocated regularly on her behalf

to obtain the widest possible range of services for her. Polly had two wheelchairs, one manual and one electric, which the local hospital half an hour's drive away serviced regularly. She was provided with a medical alarm, lifting equipment, and bi-monthly respite care. Polly said:

> I just have to ring up and she'll (Occupational Therapist) get it for me. There are things they could help me with …..but I wouldn't put them to the trouble.

Difficulties the participants' experienced with needs assessments appeared to be related to the negative attitudes and service rationing imposed by health and disability service providers.

Attitudes/Gatekeeping of Service Providers

Consumer focus and respect had remained a high priority of the health reforms. The participants described varying levels of behaviour and negative attitudes which they found unacceptable from medical staff and disability support providers. They believed the combination of funding difficulties and their rural residency meant they experienced a higher level of

rudeness and discrimination than was acceptable. It appeared to be an institutionalised problem within all sectors of the health system, and was particularly noticeable among clerical staff.

The New Zealand Health Strategy (2000) stated individuals must be treated with respect free from discrimination and harassment, and receive treatment of an appropriate standard. Criticism was continually voiced by the participants about the lack of respect shown to them. Uncaring and unrealistic attitudes expressed by specialists received particular mention. Polly felt her neurologist ruled her life, prevented her from accessing treatments which may help her, and commented 'he's quite rude, he's a doctor that hasn't any feelings at all'.

Jane was told by a specialist to go home and die, while Kiwi Mel described her 200 kilometre round trip for an appointment to see her orthopaedic surgeon as 'a nightmare'. She often waited up to five hours to see the specialist and was then in his office for 'all of three

minutes'. In contrast Sarah's experience was more positive, 'I think we have a fantastic relationship, it's one of honesty, although he occasionally tries to be PC'.

Appointments with specialists not seen regularly proved particularly difficult. Referrals were often lost, places on waiting lists reassigned by zealous staff, and inquiries as to why they had not been seen were met with comments such as 'you're not on the waiting list'. Persistence meant files were found, names mysteriously re-appeared on waiting lists, and equipment recommended by their specialist suddenly became available. All the participants believed their disability was a major factor in the negative attitudes of their specialists and other health employees.

Sharon had waited two years for an appointment with a geneticist. On inquiring how much longer she would have to wait for an appointment, she was informed that both specialists with expertise in her disability had now moved overseas to work. She asked when or where she

could expect to see another genetic specialist and was told there was no funding for a genetic clinic in her area. Sharon said: 'I honestly think doctors get paid too much. I would rather have gone to the vet to be honest, I trust him more'.

General practitioners received more compliments from participants. They had carefully chosen the person who would manage their day to day health care. Acknowledging they were often disappointed by their doctor's referral procedures, participants felt that they did not expect their general practitioner to have an in-depth knowledge of every facet of their disability.

Wide geographical areas and huge case loads covered by some doctors meant the participants were often unable to see their own general practitioner. Part time clinics in rural areas were the norm. Ambulance services were an important backup when their doctor was unavailable, but in more than one case had failed to arrive when called. Kiwi Mel reported waiting forty minutes after dislocating her hip, and when ringing

again was told the ambulance had a flat battery. In contrast, Polly had no difficulty when she rang for an ambulance. She said:

> there are three ambulances. If you call them they will come. My alarm system, if I press the buzzer it goes straight to St Johns ambulance and they are out within five or ten minutes.

Occupational therapists and physiotherapists seemed unaware of the special needs of disabled rural women. One participant described them as 'ignoramuses'. They failed to meet requests for practical and personal needs, were disrespectful, uncaring and indifferent. Sharon said:

> their attitude is that they are doing me a big favour....they don't seem to be flexible. In the old days they might work something out on the quiet for you. It's like they don't care, I only go to them if I'm in a desperate situation. Someone has always got the 'we don't support it' argument ready for you. It makes me angry because they are getting paid to help and they are not doing their job. They are not listening to you, they are making you feel worse. They put you in the "too hard basket".

Barbara, who lived in a small cabin on a remote lifestyle block, had designed a practical solution to difficulties she experienced propping herself against the kitchen bench while she prepared food. She wanted to cut a semi-circle in the bench so she could lean on it and be physically supported. She explained:

> the occupational therapist really didn't have a clue what to make of me. You could tell I was in the "too hard basket". She said 'lie down on the floor'. I'm lying there feeling really vulnerable and the one from the [name of disability support service] association started shouting at me. 'We've talked about your situation and we've decided it would just wreck the bench, but what we'll do is give you a bar stool'. I said I can't do that and she said 'what's the point of installing all this stuff if you can't use it'.

Physiotherapists employed by hospitals were often described as indifferent, leaving patients to wait for long periods of time in discomfort, even when no one else was receiving treatment. Mobile physiotherapy services were no longer available since the reforms of the early 1990s, meaning long trips for necessary treatment. Sharon was told that because her disability was not in the physiotherapist's books it did not exist.

She said: 'I never want to see another physiotherapist as long as I live'.

Obtaining servicing for wheelchairs and other equipment was usually very difficult, although Polly had both her wheelchairs serviced regularly by her local hospital. Sharon, whose wheelchair lost a wheel, was told there was no funding to come out and repair it, 'could she bring it in please'. She felt she always had to pull a guilt trip on the orthotic department staff to get them to drive twenty minutes to her home. When she rang the head of her local healthcare organisation to discuss this issue she was told because she had two wheelchairs, one for inside and one for the farm, she had already received too many favours. The healthcare supervisor stated: 'one wheelchair is a necessity, two is a luxury'. Sharon retorted: 'legs that work are a luxury in my opinion'. She was then informed there was no more help of any kind available for her.

Nursing staff in hospitals were seen as 'fantastic', caring, empathetic, and often initiated referrals for

extra home help and support. In contrast, district health nurses were usually difficult to deal with and had an attitude, noted by Sarah, that 'patients can wait'. She said when a district nurse had to visit a rural patient every day they were usually a prisoner in their home unable to leave for fear of missing the nurse.

Bureaucracy expanded with the health reforms and this meant frontline clerical and reception staff had been placed under increased pressure. They dealt with the frustrated public reaction to long waiting lists, long periods of time spent in waiting rooms, and clerical errors sometimes not of their own making.

Institutionalised gatekeeping developed as a result, meaning a simple task such as making an appointment became very difficult. Kiwi Mel was required to visit her orthopaedic surgeon on a regular basis and said:

> to get an appointment you have to argue with the receptionist, a real witch actually. You are almost on the point of crying. I've never been rude to her, I've never been nasty to her....she just treats me like a dog. One of these days I'm actually going to turn around and I'm going to pull her

up. I'm going to do it in front of a lot of people because I've had enough.

She explained that the receptionist sometimes put her file to the bottom of the pile allowing the men present to see the specialist first.

Jane's telephoned order for medical supplies invariably arrived with some equipment missing because the person on the desk failed to complete the order properly. Jane was then left alone for an extended period of time while her husband, her main caregiver, made a two hour round trip to get the missing items. He had now decided to deliver the order personally to the hospital supplies department, and he helped the clerk make up the order.

The sheer frustration experienced by the participants was frequently expressed in very critical comments about the intelligence and personalities of front line staff. While funding cutbacks were mentioned as a possible contributing cause of the rude and uncaring behaviour of receptionists, Sharon believed that

reduced funding had increased the level of 'stupidity' among staff. Noting that receptionists were getting 'nastier', she added:

> you are there cluttering up their nice tidy waiting rooms...the lacky on the desk, I can't get past her.

Sharon also described an urgent call for a repeat prescription when she let the phone ring for almost five minutes before it was answered. She said:

> they should be fired, there are plenty of people out there wanting jobs, get some nice ones. How much skill does it take to answer a phone. The doctors "I am God" attitude seems to have dribbled down to their staff as well.

When asked why they did not complain to the individual concerned, or the health service involved, the response was unanimous. None of the participants felt comfortable about complaining, fearing their services would be cut accordingly. In Sharon's words, 'you don't want to get their backs up because they will take it out on you somehow'.

District Health Boards represented in this research had advertised the way a complaint could be registered. Pamphlets describing complaint procedures were available from several sources including hospitals and general practitioners waiting rooms.

Barbara had complained repeatedly to a variety of health and disability organisations and was having difficulty obtaining any type of health service. She felt her decision to be proactive and advocate on her own behalf may have been wrong. She intended taking a more friendly approach in the future.

Kiwi Mel was very scared of making a formal complaint:

> I did write a letter, once, later….I just wished I'd never done it. Nobody's going to want to have anything to do with me.

She contemplated laying a complaint about the receptionist at the orthopaedic clinic but stated:

> mainly what has held me back from making a formal complaint….is that I've got to go back to them. I'm going to be in the system for a long

time so I don't want a black mark against my name.

Negative attitudes and the gatekeeping behaviours of disability service providers, and administrative staff, appeared to be linked to misunderstandings about the participants' rural lifestyle.

The Rural Aspect

Gender combined with disability is a double disadvantage, but living in a rural area added further obstacles for the participants in this study. Their lifestyle choice had become increasingly difficult as their disability presented unforeseen implications.

Rural society has also undergone significant change since 1984. Income structures have altered and a business-like approach to farming has meant that rural communities are not as cohesive and supportive as they were previously.

Women's organisations such as Rural Women New Zealand and the Country Women's Institute had

reduced roles or were non-existent in many districts. None of the women interviewed had been contacted by or received help from these groups, but Jane reported excellent support from neighbours with childcare and gardening when still managing her farm following her first husband's departure.

For the participants in this study a close community spirit seemed to have vanished. This may possibly be a trend across rural New Zealand which requires further research but could have been the result of the participants own inhibitions about their disability. Polly reported being invited to a women's farm discussion group in her district, but felt uncomfortable attending as they did not understand her disability. Kiwi Mel felt she had to be independent and not ask her neighbours for support.

Women who took part in this research had chosen to continue living in a rural area despite some negative commentary, criticism, embarrassment, and their inability to fulfil the expected role of rural women.

Barbara described it as an 'environment in which to experiment'.

Feelings of loneliness, marginalisation and anger resulted. All the participants had been told they should move to town. Sharon felt she was expected to:

> live in a flat tatting and watching soapies. I hate someone living so close to you you can almost touch their house when you lean out the window.

Single participants found the rural lifestyle offered security, a lowered cost of living, better food and an opportunity not to conform to society's expectations of disabled women. Developing a fierce independence, they explored and challenged their abilities and disabilities. Sharon, Barbara and Sarah had all experienced difficulties assimilating into their rural communities. Sarah commented: 'I actually think it's an advantage because I don't have to know them all if I'm not feeling well'. She also complimented rural men for their caring attitude towards disabled rural women, while Sharon felt older rural women were

extremely judgemental and often did not have time to communicate.

Many assumptions were made about the rural/disability context. When Sharon visited WINZ she found:

> they view it as a luxury lifestyle which is really quite incredible......its also a hard life. It's hard getting out in the wheelchair when its pouring with rain. If anything goes wrong you feel like you're two million miles away from help.

Jane, who lived an hour from the nearest hospital, hospice, specialist, and disability resource centre, said:

> you are definitely disadvantaged being disabled and living in a rural area. Being disabled everything takes longer anyway, so another hour on top puts one off.

Coping with the emotional effects of feeling rejected by rural communities was solved in several ways. Feelings of vulnerability, dependence, social isolation, denial, sadness and depression meant those less fortunate than themselves became a measure, with the intellectually disabled being mentioned as the 'really disabled'.

Self image had suffered in several ways. Polly, for example, described herself as 'a big blob', while Jane felt using crutches made her very obvious when visiting the city. Building a tough outer shell became the way to combat negative emotions and feeling that their bodies had let them down. All dreamt of their disability disappearing overnight, but recognised the irony in a belief that neither they, the health system, nor a higher power could fix them.

A need for emotional support and love saw all the participants develop an extremely close and intense relationship with animals. 'I can't imagine my life without some sort of animal, they are definitely my friends' said Kiwi Mel. Sharon, who had a large number of small animals, felt:

> for me they have a superior quality in that they are not judgemental. They accept you for who you are unconditionally. They are good company.

Living in a rural community meant the participants were isolated from the wide range of support networks usually available in urban areas. They had been

creative in their use of computers to network and join online discussion groups.

Support Networks

Modern technology was used to combat the negative effects of living in a rural area. Contacts had been established with other rural women as well as women with disabilities. Jane, who had a supportive network of family and friends, still found that 'computers are a lifeline.' She felt online support groups and chatrooms were useful for sharing knowledge about her disability. The internet provided a wealth of health and disability information the participants had been unable to access from the medical profession or disability organisations. It was a powerful tool for self advocacy and exploring new treatment methods.

Reluctance by the medical profession to put patients in contact with support networks or to share their knowledge had been the catalyst for the participants becoming discussion group moderators, establishing

their own support groups, and, in one case had resulted in an international on-line rescue.

Health professionals expressed a dislike of their patients sourcing medical and treatment information. Sharon was told by several doctors, who professed a lack of time to do research, that undertaking it herself was not a constructive step. Jane felt 'the specialist should at least advise patients of the websites available for their particular disease'. In contrast, Barbara was told when someone had a rare disease it was up to them to find information and educate the health professionals.

Starting an online disability support group had been life changing for Sharon. She was told on diagnosis that there were only 12 people in New Zealand with her condition. Sharon now runs a website and sends out a regular newsletter to over 600 members in New Zealand. She said:

> I started the support group in 1995 because there was nothing here. I didn't really know where we were going with it...when we got about twenty I

started a newsletter and people would send in their stories. That helped everyone know they weren't alone because it's quite an isolating condition. When you are finding someone feels the same way as you do it helps. Even talking about it to someone who's going through the same thing helps. Unless you've experienced this condition you can empathise but you can't really relate to it.

Although using a computer was difficult when fatigue, illness or a particular disability made typing awkward, internet use did offer instant responses and support. Polly had obtained some information from the internet when she was first diagnosed but was now physically unable to use her computer. Jane had been supplied with specially adapted technology and had appeared on a popular current affairs television show as a result.

Maintaining an organising role often proved difficult. Sarah joined a discussion group based in the United States and soon became the moderator. She explained: 'since I became a moderator I have found that moderators aren't allowed to be having a bad day'. However, Sarah also felt that her training as a nurse

allowed her to help these people. She said: 'I can help all these Americans, I can, with my medical knowledge I help them to cope'.

Online support networks had enriched the lives of the participants. Daily contact with other disabled people via the internet brought friendships and an international sharing of knowledge. This had allowed them to make informed choices about their disability despite the difficulties they were experiencing trying to access knowledge from their health care providers.

Conclusion

This chapter has described the impact of the health reforms on six disabled rural women. Although their knowledge of the organisations and documentation surrounding the reforms was limited, all found the reforms had changed the way they received health care. Their experiences of various health professions showed that, for the most part, the medical profession and disability support services failed to adhere to the laws, priorities and objectives of the health reforms. Despite

rural health care being included in recent reports and strategies the policies of these health documents were not being implemented. Disabled rural women had specific and identifiable needs not being met, despite assertive attention to making these needs known. Gatekeeping by clerical and other staff was identified as a major factor in this.

The next chapter analyses the research findings by comparing the aims, priorities and objectives of the health reform documents with the interview data and literature reviews. The comparative analysis offered is informed by feminist and disability theory.

Chapter Five
Analysis of the Findings

This chapter compares and analyses the health reform documents with data from the interviews in the light of issues raised in the literature reviews. Aims, objectives, priorities, understandings of and assumptions about the needs of disabled people expressed in the health reform documents and demonstrated in the attitudes and behaviours of health service providers were compared with the views and experiences of the participants. These comparisons revealed a range of interlinked and competing positions within multiple discourses around the provision of health services to disabled women in rural communities. Many of these positions within the health service sector were supported by outdated values and institutional thinking.

Seven thematic categories have been identified for detailed analysis and discussion. These are: assumptions about disability, policy language,

economic concerns, medicine and disability, disability support services, rural health, and gender issues.

Assumptions About Disability

The New Zealand Disability Strategy (2001) stated that a negative attitude towards disabled people operated at all levels of the general population. Assumptions and ignorance were experienced as stigma, prejudice and discrimination which affected behaviours and created barriers. *The Strategy's* first objective was to encourage and educate for a non-disabling society that respected and highly valued the lives of disabled people and supported inclusive communities. *The New Zealand Disability Strategy* (2001) recognised that disabled people were experts on their own experience.

Assumptions about disabled people underpinned the medical and social practices examined in this research. Morris (1991:15-23) considered 'difference' brought a feeling of not belonging, patronisation, of being 'the other' for disabled women, a view supported by Weedon (1999) and Linton (1998). Manifestations of

prejudice became assumptions which impacted on their interactions with the non-disabled world.

Participants in the present study experienced extensive prejudice, hostility and distrust at all levels of the health system and in their rural communities. Language such as "handicapped" or "cripple" was offensive, even though the participants sometimes used this same language as black humour. All the participants experienced daily prejudice based on their physical difference. Barbara summed up the participants feelings: 'the able bodied world would not have to put up with all this rubbish we have to put up with'. Frustration, sadness and anger at barriers they encountered had left the women feeling undermined, demoralised, exhausted and sometimes depressed.

Access issues reflected ignorance and uncaring attitudes. Lonsdale (1990:144-147) argued prejudicial attitude was the result of fear and a desire to exclude the disabled woman. Jane and Polly talked of times they could take part in sports, were fit, and could use

their leisure time as they chose. Thoughtless behaviour meant invitations to similar social events were now rare, friend's homes were inaccessible, and group prejudice predominated. Sarah commented that in rural communities 'social gatherings gather round the bloody table' and no one understood her inability to eat normally. They say: 'why don't you try and eat this, or why don't you take some aloe vera'. Sharon firmly believed 'attitude is my real disability'.

Lunn (1997:130-135) discussed the politics of claiming or resisting a positive disabled identity. Despite many negative experiences all the participants had developed an assertive, independent and positive attitude towards their own disability. They were unexpectedly devoid of the emotive. 'One's attitude to oneself is the most important' said Jane. Kiwi Mel commented: 'its not going to beat me, it's not going to rule my life'. Sharon agreed saying:

> there are some things I can't do. Ok, I can't get up and walk, but that's just something I can't do like other people can't sing. That's a disability in my opinion. So it's all relative. I reckon everyone has a disability. I know some people that are

physically quite healthy but are disabled in their attitude, or they are dead from the neck up.

Discrimination had meant developing a vast level of inventiveness. Peer support had counteracted the invasive role of professional power and negativity in their lives (Morris, 1991:175). Disability support networks and online discussion groups had been used as a foil to feelings of powerlessness and the failure of the medical profession to share knowledge. These networks offered practical and emotional support about coping with disability in an environment of mutual understanding.

Assumptions and misunderstandings about disability had impacted in several ways upon the lives of the participants. This was often reinforced by the language of the health policy documents (Munford, 1992, 1995).

Policy Language

New Zealand's health policy had drawn on a variety of health and economic concepts to frame the provision of health and disability services. *Choices for Healthcare:*

The Report of the Health Benefits Review (1986) established consumer focused objectives which included quality, efficiency, equity, objectivity, choice and fairness. These became the objectives and success indicators for recent policies such as *The New Zealand Health Strategy* (2000) and *The Primary Health Care Strategy* (2001). Defining and implementing these concepts varied relative to the perspective of the agency involved. Priorities set by the government, policy writers, District Health Boards and disability service providers brought a medical bias to the actioning of policy. This resulted in inequitable, inefficient and poor quality service for rural consumers. Different interpretation of terminologies became a defence for the poor or non-delivery of services to rural areas.

Discussing *The New Zealand Health Strategy* (2000) and *The New Zealand Disability Strategy* (2001), Sarah stated they were all written in 'gobbledy gook' and were 'airy fairy'. Other participants commented: 'it's all the right words' and 'it's a mission statement',

noting that politically correct language was used for 'papering over the surface'. Questioning the motives and language of policies, the participants believed they were formulated to create acceptable images and should be distrusted.

The health reforms were structured to provide quality health care. Quality reflects professional excellence and a high standard of patient care. *The New Zealand Health Strategy* (2000) stated that quality health services should be delivered efficiently, meet people's needs and be clinically sound. *The Strategy* also stated 'quality is the cornerstone of a high-performing public health and disability support service' which 'takes account of community and health service users views on quality of care' (2000:25).

Seddon (2003:95-105) discussed the difficulties inherent in defining quality. She contended its specific dimensions should include being patient-centred, timely, equitable, effective and efficient. Structures,

processes and outcomes become the pre-requisites for measuring quality.

Interview data showed health care for disabled rural women was marred by difficult patient/professional relationships, lack of choice, inequities and failure to provide practical and financial resources. Training in disability issues was minimal, referral procedures were poor, and gatekeeping medical knowledge was the norm. Modern information management systems and the use of technology proposed in the *Health Information Strategy for the Year 2000* (1996) as a method of bringing equitable health care to rural communities had not been implemented.

District Health Boards had failed to apply health, disability and rural policies aimed at providing a quality service to disabled rural women. They seemed reluctant to take responsibility for this group of clients, often arguing over their geographical boundaries. Jane commented: 'it was hopeless, I didn't really come into any area'.

Sarah believed bureaucracy did not understand 'the clinical needs of the end user', and said: 'there is no system set up for it'. Kiwi Mel supported this view saying: 'they are better than nothing', but wished 'they could go backwards in time and supply the services they had twenty years ago'.

Sharon suggested District Hospital Boards 'should be had up under the Trade Descriptions Act', agreeing with Barbara and Kiwi Mel who felt the current policy emphasis on wellbeing had violated their rights by denying them services. Complaints were weighed against a possible refusal of treatment and the need to access services for an extensive period. Kiwi Mel felt she might be seen as a nuisance and was very scared of laying a complaint.

Rural Health Policy: Meeting the Needs of Rural Communities (1999) stated that rural people were to receive effective front line care in their own community. Services were to be organised around people and their needs (1999:2). *The New Zealand*

Health Strategy (2000), *The Primary Health Care Strategy* (2001) and *The New Zealand Disability Strategy* (2001) were all premised on the concept of choice. Budgetary constraints meant making choices within competing health demands. Areas of need were to be targeted by District Health Boards. Information on accessing health and disability services, and the choices available, were to be accessible for consumers (*The New Zealand Health Strategy*, 2000:2; *The Primary Health Care Strategy*, 2001).

Choice was restricted in a variety of ways for the participants. Information had not been disseminated, Sarah stated: "I know nothing. I haven't even been handed a pamphlet'. Kiwi Mel commented: 'nothing is offered to me, I always have to ask for it or nag for it'. Funding, distance, red tape and laying the blame on their rural residency were offered as explanations. Appearing on television and in a national newspaper brought a response to Jane's request for health and disability support, but 'it was one hell of a battle to get any real help until then' she said.

Rural health services were reported as fragmented or reduced. Jane and Kiwi Mel often found themselves unable to access their own general practitioner. Jane's medical supplies had previously been delivered by a district nurse who lived nearby but this was no longer allowed. Jane also believed 'there could be other services I am eligible for but don't know about'. Kiwi Mel felt that if a family member of Helen Clark or Annette King became disabled provision of disability support would change overnight.

Seddon (2003: 95-105) defined an efficient service as one measured by fiscal responsibility achieved by maximising revenue and cost containment. Fiscal restraint appeared to mean service rationing, particularly in provision of equipment and medical care for disabled women. Polly felt the system was efficient and adequately supplied her with services and equipment, but this was not experienced by the other participants. They had long waits between referral and the provision of disability support services, often following up referrals themselves. Sharon waited six

months for a haltor monitor and was told repeatedly she was not on the waiting list for this form of testing. Accidents were mentioned as disrupting their treatment. Kiwi Mel stated: 'it sometimes annoys me….if I've been waiting on an operation and someone that's been drunk…they end up getting in front of me'.

Balance between fiscal shortfalls and efficiency was difficult to achieve. Sarah's District Health Board had been unable to provide her with essential nutrient supplies and was spending $1000 per week contracting a private firm to deliver the supplies to her home. She described many instances of being booked for surgery only to arrive at the hospital to be informed the theatre schedule had been cancelled that day. This disrupted her health care, employment and farm management. Kiwi Mel was faced with a five and a half hour wait for a short consultation with an overworked orthopaedic specialist in a hospital she felt was dirty due to funding cuts.

The New Zealand Health Strategy (2000), *The New Zealand Disability Strategy* (2001) and *Rural Health Policy: Meeting the Needs of Rural Communities* (1999) stated equitable health care should be made available to rural New Zealanders. One of the aims of *Implementing the Primary Health Care Strategy in Rural New Zealand* (2002) was to ensure equitable and effective access to an appropriate range of quality primary health care services delivered to rural communities within acceptable travel times. This was defined as 30 minutes from the nearest primary health care service. District Health Boards were directed to ensure the establishment of Primary Health Organisations in rural communities using locally devised solutions.

Equity was not in evidence in the interview data. Five participants had not received adequate care in their own communities. Living 'too far out' appeared to legitimise the refusal to provide a necessary health or disability service. Sharon and Kiwi Mel spoke with envy of friends and acquaintances in urban areas who

received sophisticated help they had been told was available only if they relocated to town. Many services the participants requested were considered normal in urban New Zealand. These included providing and repairing wheelchairs, home help, personal care and housing modifications. Jane felt rural communities were too far away from core health restructuring.

Systemic rural inequities including isolation, poor roads, unreliable telephone services and low incomes, made obtaining services increasingly difficult. General practitioners seemed to have become increasingly disinterested in rural practice and specialist services usually required travelling huge distances. Kiwi Mel spoke of travelling eight and a half hours for an MRI scan while Polly faced a drive over a long windy hill road to keep appointments with her specialist. Jane felt she could accept travelling for certain health services, but her basic needs should be met wherever she was domiciled.

Mention of accountability brought gales of laughter to the interview process. Financial and professional accountability was an essential part of the reform process. Participants believed structures to examine financial and personal accountability at all levels of the health and disability sector had not been properly defined or were absent. Accountability was viewed as a one way process. No one was made accountable to the patients or clients. Sarah believed 'there is no system set up for it', and even 'the accountants are not accountable'.

Kiwi Mel, who struggled with the responses to her residence on a remote farm said: 'they couldn't care less'. Sharon stated: 'down here in the [District Health Board area] they have spent millions putting in new offices, then you have to wait six months for an MRI scan'. Disability service providers were not made to account for failing to provide essential services, they blamed poor funding and stated that any services they could provide were a matter of luck.

Policy framed the powerful position maintained by WINZ and ACC towards disability. Both organisations had undergone a philosophy shift with increased emphasis on cost containment and market rationale (Beatson, 2004:212-219). This brought constraints which were not popular with disabled clients who already struggled with the uncaring attitude of the health system.

WINZ received particular criticism due to the abrasive nature of their interactions with participants. Left feeling extremely distressed after several appointments regarding her benefit, Sharon commented: 'WINZ can take away your livelihood if they want to, they can make your life go down the toilet if they want to'. She described WINZ staff as 'cruel, cruel and nasty'. Kiwi Mel was concerned that long term disability had become secondary to disability which occurred accidentally, feeling that 'anybody or anything for ACC gets the world thrown at them'.

The language used to frame health policies, and to justify many instances of poor health service delivery to rural New Zealand, was usually underpinned by budgetary restraints.

Economic Concerns

The New Zealand Health Strategy (2000) stated the principles of the health sector will be upheld 'within the money available'. Living within the health budget meant spending on 'what we value and which things will give us the greatest benefit' (2000:2). Fiscal constraint became the underlying tenet of health policy formulation, particularly since *Options for Healthcare in New Zealand* (Danzon and Begg, 1991) was published. Economic incentives motivated the market driven approach which had been progressively implemented following the election of the Fourth Labour Government in 1984.

The Ministry of Health was the major source of funding for disability support services. Expenditure reflected a strong external demand balanced against

internal budget constraints. Ring-fenced funding for disability support services was 19.5% of the total Vote:Health, a sum of $1.346 billion. Needs assessments, rehabilitation, home-based support, carer and respite care delivered by private not-for-profit organisations used the major portion of the allocated budget. Increased expenditure since the 1996/97 financial year reflected an increased service usage and price increases (*Disability Support Services: Increasing Participation and Independence*, 2002:6-8).

Rural Expert Advisory Group members designated to implement *The Primary Health Care Strategy* (2001) in rural New Zealand recommended a 'nationally consistent needs based formula for primary health care'(*Implementing the Primary Health Care Strategy in Rural New Zealand*, 2002:5). This was expected to sustain basic health services in rural communities. Population based funding formulas were regarded as the best method of delivering equity. Difficulties defining rural allowances due to wide population dispersal and higher per capita costs had been caused

by using historical formulas. Concern was expressed about the funder/provider split, and the ability of District Health Boards to offer a cost efficient service (Adam, 2003:31-33).

Mandated to provide an equitable, accessible, appropriate and sustainable health care to rural areas, District Health Boards jeopardised these goals by economic prioritising and rationing of services. Directing resources to scattered populations with the greatest need had brought difficulties balancing credibility against affordability. Some District Health Boards suggested they would develop and document decision making processes linking resource allocation to the health and disability strategies in the future (Gauld, 2001:179-211).

Personal circumstances exposed the irrelevance of managed funding, rural budgeting formulas and conflicts of interest. The commercial and market orientated approach to health and disability services brought the comment from Sarah: 'the system isn't

protecting me, its only protecting some idiot working in an office'. Sharon and Kiwi Mel felt budget allocations spent on hospital bureaucracies would be better spent on rural health care.

Waiting lists and spending on new office buildings were mentioned as examples of financial mismanagement. Sarah, who worked in the health system, reported the cutting of red tape and the red carpet being laid out when hospital board members or their families needed surgery or treatment. Kiwi Mel spoke of a newspaper report which stated that seventeen or eighteen people employed by her District Health Board earned over $120,000 and she wondered 'just who was getting all that money'.

Applications for disability support had frequently been refused 'because we haven't got the money'. This included simple care such as wheelchair repairs, home help, the cancellation of specialist clinics and cutting back services such as mobile physiotherapy. Participants' found it difficult to challenge economic

and medical terminologies used as excuses. Only Polly was able to say 'the health system has come to the party'.

Misconceptions about the rural lifestyle and its economic circumstances were frequently experienced. Rural New Zealand had experienced complex economic changes since 1984 with repercussions that included reduced incomes and increased dependence on the state health system. None of the participants were able to afford private medical insurance, 'I have no money to pursue my choice of healthcare outside the system' said Barbara. Jane was told farmers were wealthy and should not depend on the state for assistance, bringing a reluctance to do so. Expensive but necessary drug regimes not funded by Pharmac quickly became unaffordable. Resorting to generic drugs or the philanthropy of friends became the only alternative.

Rural residence brought unseen costs to disabled women. Specialist care not provided locally was often

difficult to obtain financially. Petrol was expensive and requesting partners take time off work to transport them to appointments increased the financial strain. Jane incurred accommodation costs as exhaustion meant she could not muster the energy to travel home the same day as her appointments. Trips to town were usually restricted to one a week or less, a request to 'come in tomorrow' showed little consideration to disability or the financial cost of a further visit to town. Those living on a benefit found it difficult to explain their circumstances when doctors suggested special diets, special clothing, and extra drugs.

Sharon, Barbara and Kiwi Mel wished to try alternative treatments because these practitioners 'do not deal in labels'. Charges were not covered by community service cards or WINZ and consequently were unaffordable. Treatments such as glucosamine and flax oil which had offered pain relief and better health were not funded by the health system.

Fiscal constraints and participant concerns that budget allocations did not take health consumers into consideration were indicative of the role various health sectors had played in maintaining the medical model of disability.

Medicine and Disability

The medical profession is a powerful social group with prestige and influence. Society accords them a status which brings both respect and deference. Their social authority is derived from professional cognitive authority, their position within powerful institutions, and social connections which allow their authority to operate beyond the medical institution. This power/knowledge base brings with it sophisticated social control and gatekeeping with a patriarchal base and contradictory agendas (Beatson, 2004:121; Munford, 1992, 1995; Oliver, 1990, 1996; Wendell, 1996:117).

Acting on their understanding of the medical model of disability, professional interactions with the

participants were configured by outdated perceptions of disability (Oliver, 1996). Re-definition of disability, 'it's now acceptable to say you are disabled' said Barbara, had made little impact. These viewpoints legitimated the medical, institutional and social management of participant's lives (Drake, 1996:149). Emphasis was placed on a clinical diagnosis, participant's were treated as ill, classified as victims who were not quite perfect, passive and helpless (Oliver, 1990).

The fundamental control of the medical profession over the private lives of the participants was difficult to deny. Doctors used their knowledge and skills to treat the socially constructed disability rather than the physical impairment. Their response to the women's impairment had a significant impact on their experience of primary health care (Begum, 1996:185). Professional and powerful attitudes had been transferred to disability support staff and service providers by default. Inappropriate medical thinking was imposed, usually making the doctor/patient

encounter difficult. The women who took part in this research were frequently unable to negotiate with their doctors. Polly was very nervous about appointments with her neurologist and said: 'he was ruling my life. He said I couldn't have something I hoped would help'. Barbara, Sharon and Kiwi Mel suggested that doctors saw themselves as God, but Sarah said:

> I don't think there is any doctor who would ever think they were God....no doctor actually believes they are God, they suffer severe insecurity problems.

Specialists received particular mention as undermining trust, confidence and self esteem. Those encountered in hospitals had entrenched attitudes which were difficult to confront. Personal experience was often dismissed when accepting the scientific role of "patient" in the consultation process. This was confusing and alienating. Kiwi Mel reported her doctors as being 'very offhand'. Sharon described her difficult long term relationship with the medical profession saying: 'if I saw a doctor I would start crying'.

Wendell (1996) has acknowledged a vocabulary of illness that alienated and objectified disabled women. She argued that 'patients cease to expect acknowledgement of their subjective suffering or help in living with it' (ibid:120). Participants were left to choose between their discomfort and pain, or the supposed expertise of the doctor. Needing to take control of their own health and disability needs meant they had often been forced to medicalise themselves to obtain necessary help (Davis and Dew, 1999:33).

Sarah's experience working in the health system had taught her that medical pride often took precedence over patients. Although she commented: 'my GP is a darling, he came in down the track and he tries his best to cope and understand', she found doctors were unwilling to admit they did not know what to do, and instead question the sanity of the patient. Psychosomatic diagnoses were a normal experience. In Sharon's words:

> they can take away a pain, they can make your life easier or harder. But sometimes you are

given a placebo. You are worrying too much about your health, go away, don't bother me.

Boundary crossing was not encouraged. Referring patients to other doctors or specialists occurred rarely. Sourcing specialist care themselves was seen as inappropriate. Accessing information via the internet and from discussion group members was discouraged, although, as Jane said: 'technology, if one can afford it, helps these days'. Sharon, Polly and Jane had been told not to use information they gathered by this method, although Barbara was expected to educate the professionals involved in her care. Jane felt doctors wanted to keep medical information and knowledge to themselves.

Difficulties the participants experienced with the medical profession also occurred frequently during their needs assessment process and their contact with various disability support service organisations.

Disability Support Services

Community based services to ensure disabled people were supported to live in their own communities was one of the action points of *The New Zealand Disability Strategy* (2001). Disabled people's abilities were not to be questioned, and a valuable interdependence with support organisations would be recognised. This document also acknowledged that accessing disability support services could be disabling because they may not be flexible enough to meet individual needs (*The New Zealand Disability Strategy*, 2001:1-10).

Disability support providers were to ensure disabled people had trust in a system which treated them with respect. They were not to make inequalities worse, they were to increase people's control over their own lives, foster social inclusion and minimise stigmatisation. Access systems were to be flexible, staff responsive to needs supported by education and training in disability, and linkages across health services were to be co-ordinated (*Support for Independence*, 1992; *Disability*

Support Services: Increasing Participation and Independence, 2002).

The health reform process increased the power of allied medical professionals such as physiotherapists and occupational therapists. Not-for-profit organisations had proliferated, gaining an often undeserved expert status. Intervention and intrusion in the lives of disabled people was premised on a limited knowledge base (Oliver, 1996:37). Sharon was told that because her condition was not in the physiotherapy books it did not exist.

Rehabilitation geared towards restoring normality had become what Oliver (1996:103-108) described as an ideological exercise of power by one group over another. Social relationships associated with therapy were of themselves disabling. Rejecting the rehabilitation process exposed misguided interpretations and normative assumptions were reformulated. Sharon believed that 'when they started calling you a client I found that everything went

downhill. I preferred it when we had just no name at all'.

Consumers were usually not treated with fairness, dignity and respect. Power exercised by needs assessors made Barbara comment she never wanted to see another needs assessor again. She was humiliated when asked to lie on the floor by an occupational therapist and stated: 'I'm lying there feeling really vulnerable, people looking down at me, and the one from the [name of disability support service] started shouting at me'. Sarah felt 'it would be nice for somebody to say is there anything, what are you having problems with'. Sharon was described as a hermit by the manager of a disability support service who repeated his assessment of the situation to her proposed home help.

Reading a list of available disability support services mentioned in a variety of health documents to participants was met by incredulity and sarcastic laughter. They had no idea such a wide range of

services existed. Sharon wondered if it suited disability support services to have large amounts of red tape between the client and the help they were supposed to offer. She had been told 'we can't do this because section blah blah of rule such and such says we can't'. Sharon felt that health service providers had made concessions to fit difficult circumstances until strategies such as *The New Zealand Health Strategy* (2000) were implemented.

Individual outcome foci were criticised by the participants. They often felt patronised, particularly in regard to where they chose to live. Jane, who became totally dependent when single-handedly raising two children and running a farm, was offered 13 hours home help a week, an unrealistic solution to her situation. Barbara commented on a service provider's inability to listen to her needs and said: 'they can't think laterally'.

Funding restraints appeared to have reduced choice, making the delivery of services to rural areas

inadequate. Reported by five of the participants as being minimal, disjointed, fragmented and irregular, they were seen as driven by service providers rather than clients. This was contradicted by Polly who had been inundated with services for which she was extremely grateful. She said: I've got nothing to complain about'.

District Health Boards funded a health and disability workforce which often lacked training in the needs of disabled rural consumers. Sharon and Barbara believed most of the disability support organisations were self serving and had been established solely to obtain government funding. 'They are all doing their own thing, getting their own funding, their own little kingdom' said Sharon. Barbara felt most of the disability groups were 'useless' and could not understand why they continued to be funded.

Care-giving was driven by regulations imposed by OSH and the ACC. The women appeared to be secondary to regulations imposed on their service

provider. 'There is more that they are unwilling to do than when I first started off all those years ago' said Kiwi Mel. She needed someone who would sweep paths, remove cobwebs, clean her windows and shop for her. Kiwi Mel also spoke of a relief home help who went to sleep at her kitchen table. Sarah believed 'caregivers have absolutely no knowledge of those they are caring for', while Jane had arranged for her care to be bulk funded so she could employ her own caregivers.

Requests for help were often refused because of distance or perceived wealth. 'No one wants to go out and do it in a rural area' said Kiwi Mel. Sharon had explained that she lived only twenty minutes from town but she was told 'you live too far out'. When applying for a support service the administrative paperwork and misconceptions about their wealth made contact with support organisations particularly difficult.

Receptionists had played a gatekeeping role which prevented the participants having easy access to doctors, disability support organisations and adequate treatment. Fear of 'being treated like a dog', refused care, or having to pay for it themselves prevented participants taking applications further or laying complaints.

A failure to adequately link disability and rehabilitation services with rural consumers was usually blamed on a lack of funding and perceived isolation. The health sector appeared to have given little consideration to the difficult circumstances which could occur for women coping with disability in a rural community.

Rural Health

Research on rural health had shown a need for appropriate services to be accessible, available and affordable (Panelli and Gallagher, 2004). Rural New Zealand has features which make achieving this difficult. Service providers should be funded to ensure disabled people are effectively linked with co-

ordinated support (*Reducing Inequalities in Health*, 2002).

Health infrastructures had not supported the provision of basic health and disability support services in most rural areas. District Health Board boundaries were ill defined and participants had often fallen through the cracks. Rural residency was viewed as "difference", with poor needs assessments and the failure to provide regular basic services an acceptable outcome. The participants all acknowledged choosing to live in a rural community offered reduced health care options, and agreed they may have to travel to access some services (*Rural Health Policy: Meeting the Needs of Rural Communities*, 1999). 'Support services are only in the cities which are far away' noted Jane, and Sarah felt that the health and hospital system made no attempt to understand conflicts between the rural lifestyle and disability. She required frequent surgical procedures and spent days organising feed for animals on her lifestyle block when she was to be admitted to hospital. On arrival at the hospital she was often informed her

procedure had been cancelled and could she please return the following day.

Health bureaucracies constructed rural women in accordance with long established power relationships in farming communities. Rural women were seen as being physically capable, competent, self reliant and determined. They had become increasingly involved in a partnership role and the strenuous physical rural lifestyle (Grace and Lennie, 1998; Little and Austin, 1996; Saugeres, 2002).

Disability brings the inability to conform to rural biological, physical, cultural and gender expectations. Grace and Lennie (1998.366) found 'cultural practices constitute a significant barrier to women's full participation' making it difficult to construct a disabled rural identity. Disabled women were unable to fulfil the valuable feminine rural attributes such as caring, self sacrifice and determination (Saugeres, 2002). Being called 'that handicapped person' caused great distress to Sharon who was working towards integrating into

her local community. She commented: 'they cannot understand, they only focus on the negatives of your situation'.

Physical aspects of the rural lifestyle were extremely difficult to deal with. Weather extremes brought intense pain and physical discomfort making all work difficult. Descriptions of single-handed construction of fences and cattle yards were offered with a sense of pride and satisfaction; yet knowing their work had not met accepted rural standards. Ensuring she had a continous water supply was a huge worry for Sharon who found it difficult to find the source of leaks and carry out repairs.

Rural communities had changed during the last two decades. The participants suggested that the expected sense of 'community' and 'caring' no longer existed. Rural images and long-standing institutions were sustained by the masculine nature of farming (Little, 1987; Whatmore, 1991). Having made a conscious decision to live or stay in a rural area when becoming

disabled, the participants reported enjoying the independence and freedom, peace and quiet. Polly described the countryside as 'a haven'. They also found rural New Zealand had been subjected to unexpected changes.

Jane described a community where 'the neighbours kept me going', but other participants felt community spirit had been replaced by a lack of communication. In Sharon's words:

> I've seen how farming people are towards each other, how they help each other. They are there if you are in need, but I don't find that here. Mind you....if you haven't lived there for 50 years you're not really accepted.

Rural women 'are no longer staying at home making scones' she said. Many have been employed off the farm. Sarah found 'there is nobody down the road anymore who could come and help'. Rural women who chose to become a labour unit on the farm now attend farm discussion groups rather than calling in for a cup of tea, and were unavailable in a crisis. 'You are just left to deal with it, to get on with it' said Kiwi Mel.

When asked how she felt about this she said: 'I probably wouldn't want to go there because if I did start thinking too much about it, it would annoy me'.

Women's organisations which had previously supported ill or disabled rural women have either ceased to exist or have a more limited role. Many of these groups do not appear to have an understanding of the way disability is socially constructed (Munford, 1995:33). Negative attitudes towards disability were also experienced from rural servicing agencies including banks and stock and station agents. Jane, who applied for a bank loan so she could remain on her farm, said:

> I was turned down because I was a disabled woman. I had to borrow privately when I should have easily got the loan.

Kiwi Mel believed stock agents still prefer to talk to men, describing an incident where an agent was prepared to drive two hours to their runoff to speak with her husband rather than talk to her. She suggested that: 'they know they'd get a flea in their ear if they didn't talk to me'.

Residing in a rural area had been enjoyable but also presented some difficulties for the participants. Their satisfaction with the rural lifestyle was tempered sometimes by the difficulties they encountered as disabled women.

Gender Issues

Gender discrimination had occurred at several levels of the health system. It was usually subtle, although the participants believed their disabled identity usually preceded their gendered identity (Lunn, 1997; Sherry and Chenoweth, 2000). *The New Zealand Disability Strategy* (2001) and the *Action Plan for New Zealand Women* (2004) prioritised gender issues for rural women and women with disabilities. Women were to be offered equitable, appropriate and welcoming access to services.

Gender often explained why the women received less than adequate health care (Tong, 2002:202; Begum, 1996:185). It had a significant impact on their health and primary health care experiences. 'There are little

things that happen that make you seethe with anger because they wouldn't do that to a man' said Kiwi Mel. Discrimination was not always visible, but it impacted on every aspect of the patient/provider relationship. Kiwi Mel had repressed strong emotions related to her experiences with the hospital receptionist, saying: 'that witch at [name of hospital], she's nice to men….I've never seen her be rude to or get up and put the men's files down to the bottom of the pile'.

'Medicine reinforces the image of women as emotional, passive, dependent, feminine, seductive, manipulative, subjective and untrustworthy' (Davis and Dew, 1999:30). Doctors were reported as judging disabled women and having a definite attitude problem towards them. 'The doctor says you're hysterical, or you haven't got enough to do, you're hormonal or whatever' said Sharon. The participants believed their disabilities were misunderstood and this resulted in the lack of constructive help. Doctors appeared to support the "out of sight out of mind" scenario.

Specialists were reported as rude and as having failed to offer normal medical interventions to the women. When asked if she had been taught breast self examination, undergone cervical smears or received contraceptive advice Sharon replied: 'no one has ever mentioned that I have any of it'. She had a family history of breast cancer but had never been offered a mammogram. Barbara had a family history of cervical cancer but had never undergone a cervical smear test; she admitted to being very nervous about the outcome of such procedures.

Negative perceptions of gender and women's inability to fulfil customary role expectations affected the self image and self esteem of the participants. This often resulted in feelings of 'difference' and a fear of dependency (Munford, 1992, 1995). Morris (1991:97) discussed autonomy versus dependency and the negative reactions which may occur. Participants experienced sadness at having to rely on family members, at being unable to undertake farm chores, gain employment or take an active part in their

community. Requesting help often proved difficult and a fear of being turned down was overwhelming at times. Polly expressed guilt at having to ask her partner to help with basic tasks such as putting her bra on and taking it off. She said: 'it makes me feel that I've got to rely on somebody and I feel that…if somebody doesn't want to why should they'. She said she was glad she could still go to the toilet independently.

Morris (1991:29) and Lunn (1997:153-157) described the fascination and consuming curiosity non-disabled people have about the intimate aspects of disabled women's private lives. Disability was expected to rob women of their sexuality and the right to an intimate relationship. Sharon felt she was not seen as a complete woman, and said:

> they wonder how does she go to the loo, does she have a catheter. I think most men if they meet a woman in a wheelchair wonder, they just wonder if you can do it or not really. Some of the comments I have heard about women in wheelchairs from men are absolutely foul. I have a friend who cannot believe we have feelings, that we would even want a sex life.

Disabled women are particularly affected by perceptions of the body beautiful and femininity (Frank, 1988; Wendell, 1996:85-116). Media representations of women's bodies play a pivotal in role in this; Sharon wished she had Elle McPherson's body. Disabled feminists have tried to project more realistic body images, but feminist theory has paid insufficient attention to issues surrounding the disabled body.

Thomas (1999b:52) discussed the imposition of 'society's notions of what is acceptable appearance', a view reinforced by Sullivan (1996) who described the embarrassment often experienced by those with a paralysed body. Polly described herself as 'a big blob', with a body that was 'taking up too much space', expressing a wish to be invisible. 'I feel embarrassed for what has happened, now I'm like this. I feel embarrassed because I can't walk'. This was reinforced by her specialist who had made frequent comments on her weight since she became wheelchair bound. Jane was frustrated by the changes that had occurred to her

body, saying: 'I had a good clean life and kept slim and fit'. Kiwi Mel wanted new teeth to replace those damaged by continually taking prescribed antibiotics, to be able to 'touch her toes', and have 'straight hands'.

Disability had threatened the participants' perception of themselves as women. They felt their bodies and the medical profession had let them down. An increasing need for personal care and public curiosity about their disability, and its impact on intimate aspects of their lives, had removed some of their privacy.

Conclusion

This chapter has compared and analysed the intentions, aims and objectives of the health reform documents against participant experiences of the health system and the literature reviews. Assumptions informed by the medical model of disability had permeated every level of the disability sector, medical, allied medical professions and rural New Zealand. Economic policies and gender impacted on the treatment and provision of health and disability support services. The final section

of this thesis will offer some conclusions and recommendations.

Conclusions and Recommendations

Conclusions

The aim of this research was to determine the impact of New Zealand's health reforms implemented since 1984 on disabled women who live in rural communities. Six disabled rural women who had regular ongoing contact with the health system were interviewed. Analysis of the interview data determined there was a wide disjuncture between the intended outcome of the health reforms and the experiences of the participants.

One participant, Polly, received excellent health and disability support services. Multiple Sclerosis had progressed rapidly and she was supported by a multi-disciplinary collaborative team approach who met all her needs. Equipment and care had been provided without hesitation, and counselling and respite care were always available for her. Polly's only criticism was of the negative attitude of her specialist. She was happy, supported by her local community, and had retained her independence and dignity.

Polly's experience showed that policy could be effectively implemented, and her care offered a model for all District Health Boards, health and disability support providers and rural communities.

The experiences of the other five participants, however, revealed significant deficiencies in the provision of health services to disabled rural women. Six key findings have been identified which underlie these disparities. These are: assumptions about disability, medical model of disability, health policy, disability support service failures, rural communities and information dissemination.

Discriminatory assumptions and prejudice towards disabled people were evident at every level of the health system. Ignorance had created barriers that were at times insurmountable. Assumptions and misunderstandings had led, on occasion, to verbal, psychological and emotional abuse. This made the participants feel devalued, depressed and marginalised. Service provision failures were often the result of

assumptions about their rural lifestyle. Negative responses had prevented the women requesting extra care or laying a complaint. Projecting a positive attitude about themselves had not alleviated their situation.

Distinctions between illness and disability were underpinned by the personal tragedy/medical model of disability. This had influenced policy formulation, attitudes, and health care. Doctors appeared to lack an understanding of a collaborative systems approach and resorted to an "individual" model which involved naming and blaming. Doctors and disability support organisations exhibited a cognitive and gatekeeping role which allowed them to control the women's lives, bodies, disabilities and emotions. Medicalising themselves to obtain necessary treatment and care had been partially successful. The continual discrimination and frustration had resulted in the participants also resorting to an "individual" model, naming and blaming key front-line personnel at various levels within the health sector.

Clear national and local strategies to bring quality health care to disabled rural women were, except in the case of Polly, lacking. Recent health strategies focusing on traditional approaches using aims, goals and objectives to providing health care had, for five of the six participants in this study, proved ineffective. Market driven fiscal considerations and the medical model of disability appeared to underpin health philosophies. Policy language proved difficult for the lay person to understand or analyse.

Consultation between the health and disability sector, policy writers, analysts and a wide consumer base had seldom occurred in the planning stages. Organisations with several agendas had represented rural health consumers. Health strategies had not been well circulated to the public, and guidelines for their implementation did not appear to exist. Policies directed at healthy communities and individual wellbeing often proved detrimental to disabled people. Targeted population health objectives had little relevance to the participants.

Support services for disabled rural women were poorly organised, unprofessional, institutionalised, lacked accountability and were difficult to access. Knowledge about disability organisations had usually been obtained privately and often accidentally. This was blamed on funding constraints and a fragmented service.

Emergence of the large not-for-profit disability support sector had changed and impacted on the supply of disability services. Management level attrition resulted in lost knowledge, poor continuity, and new employees who lacked knowledge of disability. Growing co-dependency between a self-serving disability support sector and users was evident.

Processing referrals was slow and follow-up phone calls failed to initiate rapid responses. Needs assessments were difficult to arrange for rural clients and appeared subject to pre-conceived sets of rules and regulations. Misconceptions about the types of care

required and the income of rural residents was an underlying factor.

Personal care, home help and equipment was often grudgingly provided. Needs assessors were frequently rude, offhand, demeaning, and projected the impression they were doing the participants a favour. Disability support employees were often instrumental in causing further disability. Serious illness, increasing disability, obstacles and refusals had not prevented the participants showing determination in obtaining the support they required.

Rural communities varied in their response to the participants. Attitudes and assumptions differed, several of the participants felt isolated and unwanted by their neighbours. Help with problems such as fixing water pipes or building fences was rare. Offers to feed or care for stock, gardening or companionship were infrequent. Assumptions had been made about the women, their circumstances, disabilities and abilities.

These attitudes appeared to have been affected by the economic and social changes to the commercial structure of rural New Zealand which had occurred parallel to the health reforms. Repeated refusals by service providers to travel to rural areas increased disability, health problems and highlighted issues of access. Encouragement from support staff to relocate to an urban area did little to alleviate this. The long term serious nature of the participants' disabilities was seldom acknowledged and the women were frequently forced to cope alone.

Medical services were reduced in most areas and consultation with a nominated general practitioner was frequently difficult. Mobile clinics had been cancelled which meant travelling long distances to centralised services. Emergency services often failed to offer an adequate or reliable coverage.

One significant response to the lack of emotional support and understanding that emerged in this study and is supported by other research (Blankman, 2002;

Cross, 1998; McCullough, 1986) was participants' developing very close bonds with their animals.

Information about health and disability services, health strategies, legislation and self-help support organisations was not readily available to participants. They knew little about the structure of the disability sector, what services were available, or how to lay a complaint. Knowledge had been obtained by word of mouth or personal research. Those who used various media to try and help themselves were often castigated. Support groups, the internet and contact with those with similar disabilities were the main source of information gathering.

Proposals for wide ranging information dissemination, using broadband and other technology as well as telemedicine, had not been instigated. Reduced choice, inequities and a poor level of quality service had resulted.

Recommendations

Assumptions About Disability

While attitudinal change may be stated as a policy priority, it is something that cannot be compelled in any procedural sense. However, the government and the political wing of the disability sector need to further encourage New Zealand society to implement the aims and objectives of *The New Zealand Disability Strategy* (2001). Facilitators for this could be the Office for Disability Issues, the Ministry of Health's Disability Directorate, the Disabled Persons Assembly and other well established service organisations.

Training and education about disability for medical professionals, allied professions such as occupational therapy, and disability support organisation management and their employees should be instigated. Medical schools could include this in their curriculum. Attending a training course might become part of an employment contract. Disabled people, particularly women, could be an integral part of the education process.

First contact personnel such as receptionists and caregivers should receive basic training in impairment, disability, and respecting the rights of disabled people. They could be taught to value patients and clients and treat them with dignity and consideration. Listening and advanced conversation skills training may be useful supplements to this. A rural component would be of advantage in all training programmes.

Medical Model of Disability

Viewing disability as a medical tragedy, as something to be cured, should be modified. The "individual" approach could be replaced with quality social systems which should change attitudes, practice management and service provision. The medical profession could take the lead in influencing future policy to reflect the principles of the social model of disability.

Examples of appropriate social systems would include: consultation with disabled women about their medical treatment and the rehabilitation process; treating the presenting illnesses and problems, not the disability;

removing cognitive and emotional control over their lives; and promoting a positive attitude through language and action about the disabled body.

User-friendly physical modifications could be made to the layout of hospital clinics, doctor's surgeries and waiting rooms to reduce the impact of powerful and intimidating medical surroundings on disabled people. Implementing systems to assure fairness in appointments and waiting lists is important.

Health Policy

Health policy needs to be relevant, realistic, easily understood and targeted at the individual health consumer. Guidelines for implementation could be provided for all levels of the health sector. Reasons for previous failure can be identified and targeted for re-evaluation. Key needs could be acknowledged using a group planning process which includes wider community consultation. Planning from the bottom up would allow a better identification of priorities for the suitable allocation of resources. Strategies framed by

goals, aims and objectives could be replaced by those based on performance targets and measurement indicators. Increasing policy integration between the health, social and economic sectors would be an advantage.

Rural health policies need to be focused on the rural health consumer as well as the rural workforce. Sustainable funding through primary health care initiatives for high need groups could include disabled rural women.

Government ministers, the Ministry of Health, policy writers, analysts and disability sector employees at all levels need to consult regularly with rural health and disability service consumers. If necessary, they must get in their cars, travel to rural areas, put on their gumboots, and spend time with disabled rural women to understand the impact that disability and poor service provision has on their lives.

District Health Boards could instigate policy to allow for cost effective ring-fenced budgeting allocations for disability service providers in rural areas. Removal of competition by allocating audited contracts and offering incentives to specifically selected organisations would ensure long-term stable service in rural communities. Regular evaluations of service could be planned through focus groups and consultation.

Disability Support Service Failures

Client focused, practical and comprehensive service provision guidelines for rural populations should be established. Need rather than geographical location or income must be the deciding criteria. Rural clients who wish to remain in their own homes should be encouraged and supported to do so. Service organisations who offer extensive services to rural areas can be consulted when planning changes to service provision.

Disability sector groups should receive leadership and sustainable governance training. They need to develop collaborative alliances and rural networks. Committed and skilled professional staff can receive training in rural disability issues. Requiring employees to be understanding, adaptable, knowledgeable and empathetic is important. They should be encouraged to take a positive interest in servicing rural clients. Concessions can be made to specific rural care needs such as extra housework. Implementing a system of reverse accountability to gauge client satisfaction could be considered.

Needs assessments and provision of service should be prompt. Available services and application procedures should be explained in detail, and clients should be listened to rather than told their own needs. Provision of equipment must be prompt and repairs undertaken quickly in the client's home wherever practical.

Other practical changes could include the re-establishment of mobile clinics and increasing the

services offered by the mobile surgery bus allowing it to travel to a greater range of areas. Telemedicine and patient information systems using single administrative record-keeping to document integrated care would remove significant delays. Incentives to the rural workforce could be extended, and a more comprehensive role for district nurses could be considered.

Rural Communities

Disabled rural women need increased acceptance and support from their local communities. Education through local initiatives can play a major role in this. They could become more proactive in mixing with their local communities to foster interdependence and an understanding of disability.

The Country Women's Institute, Rural Women New Zealand and other rural groups could be encouraged to offer ongoing companionship and support to disabled women in their communities.

Hospital, doctor, specialist and needs assessment appointments should be made at times suitable for rural clients. Effort must be made to understand distances to be travelled, emotional issues, physical isolation and the financial difficulties experienced by disabled rural women. Rural residency should not preclude first class reliable medical care.

Farming publications, radio and television programmes and other rural media need to be encouraged to include features about disabled women. Interviews and photographs would educate and offer worthwhile exchanges of knowledge.

Information Dissemination

Wide dissemination of information is a requirement of all health and disability services. Undertaking this could become necessary for funding applications and checking it has occurred can be done regularly during the audit process. Oversupplying information is preferable to a failure to share information. Information service officers could be employed to do this.

Disability service providers, methods of access, health and disability information and informative websites could be published in a "black book". Lists of specialists, support groups and questions to ask medical professionals or disability staff could be included. How to approach WINZ and the ACC to discuss benefits and health issues would be useful information to incorporate. This book could be given to patients, their families, or other caregivers on diagnosis. Doctors and needs assessors need to be more proactive in linking their patients and clients with other services, support groups and internet information.

Contact details for disability service providers, support groups and online support networks needs to be published in pamphlet form and placed in a wider range of waiting rooms and clinics, not just those with a medical focus. Pamphlets need to be more comprehensive and include in-depth information. They should be visible and easily accessed in waiting rooms.

Reflections on the Research Process

In concluding this research I continue to be humbled by the courage and fortitude of the participants. My desire to validate the lives of this silenced group of rural women has been tempered by their experiences in trying to cope with overwhelming disabilities. The participants' contact with the health system had, in the main, been an appalling experience which continues to sadden me.

My role as an insider in this project became increasingly complex. I had to negotiate a role for myself between the contexts of disability, gender, rurality, difference, and the participants' narratives. At times I found it extremely difficult to write from a perspective of detached objectivity. My own autobiography and long-term contact with the health system meant I identified with the participants at a level I felt they did not always understand. My frustration and anger at my own rural community and the interactions I had with various sectors of the health system during the research process intervened at times.

These included attending the birth of my twin grandchildren, two major eye surgeries, and several minor ophthalmic procedures.

I experienced some discomfort when defined as an "academic expert". An expectation that I could somehow effect change through this research I found difficult to dispel. As a result I learnt that the truth is not the same for everyone and listening is a privilege.

Difficulties I experienced recruiting suitable participants could have been avoided by more careful consideration of the possible size of the research population and a longer period of recruitment. This may have allowed prospective participants to examine their own thoughts and feelings about defining themselves as disabled before making contact. Enthusiastic recruitment by one needs assessor caused some embarrassment on my part when I had to exclude from this study those women she had selected.

Telephone and email interviewing proved successful, giving me rich data to analyse. Meeting three of the participants, one at the conclusion of the interview process, gave me particular pleasure. It reinforced the incredible difficulties these women had overcome to share their lives with me.

Transcribing the interview tapes proved to be very time consuming and difficult. Further structuring and shortening of the interviews, which is not always possible with an enthusiastic participant, would have made this process less stressful. Conducting a third interview may have been more appropriate. Employing the services of a professional transcriber should have been considered. Additionally, the decision to write this thesis in a large font was correct. By the conclusion of the research process deteriorating eyesight meant I was having difficulty reading the font size I had initially chosen.

Ethical issues which arose during the research process continue to concern me. The rarity of three of the

participants' disabilities could lead to their eventual identification. Media involvement may not have been a wise choice on my part, but at the time appeared to be a useful medium to contact possible participants.

Despite the mostly negative and difficult experiences the participants had encountered with the health system, they had adapted. They were active in suggesting changes they hoped would help others in their situation, and stated this was the main reason they had agreed to take part in this project. Their honesty and openness in sharing their lives with me means their voices are no longer silent.

This thesis offers many possibilities for future research. Social policy, health, disability, rural or feminist scholarship could address issues which are beyond the scope of this study. *The New Zealand Health Strategy* (2000), *The New Zealand Disability Strategy* (2001), and *Primary Health Care Strategy* (2001) could be analysed and measured against other groups of health consumers. Health issues experienced by disabled

women remain a concern of consumers and disability organisations. Disabled women who reside in rural New Zealand present many opportunities for future research. Imagination, passion, inventive research methods and dialogues could contribute to a better understanding of the lives of disabled women.

Appendices

Appendix 1: The New Zealand Government 1984-2004

Appendix 2: Structure of the New Zealand Health
System 1984-2004

Appendix 3: Massey University Human Ethics
Approval

Appendix 4: Advertisement for Research Participants

Appendix 5: Consent Form

Appendix 6: Information Sheet

Appendix 7: Questionnaire

Appendix 1

The New Zealand Government 1984-2004

Labour Government: 26th July 1984-2nd November 1990

Prime Ministers
David Lange   26th July 1984-8th August 1989
Geoffrey Palmer   8th August 1989-4th September 1990
Michael Moore   4th September 1990-2nd November 1990

Ministers of Health
Michael Bassett   26th July 1984-24th August 1987
David Caygill   24th August 1987-30th January 1989
Helen Clark   30th January 1989-2nd November 1990

Health Publications

Choices for Health Care: Report of the Health Benefits Review (1986)

Unshackling the Hospitals: Report of the Hospital and Related Services Taskforce (1988)

Health: A Prescription for Change (1988)

National Government: 2nd November 1990-12th October 1996

Prime Minister
James Bolger 2nd November 1990-12th October 1996

Ministers of Health
Simon Upton 2nd November 1990-27th March 1993
Bill Birch 27th March 1993-29th November 1993
Jenny Shipley 29th November 1993-16th December 1996

Health Publications

Your Health and the Public Health (1991)

Support for Independence (1992)

Support for Independence for People With Disabilities: a New Deal: A Government Statement on the Funding and Delivery of Health and Disability Services (1992)

Advancing Health in New Zealand (1995)

Health Information Strategy for the Year 2000 (1996)

Health Services 1996: Facts on the Purchasing and Provision of Health and Disability Support Services (1996)

National-New Zealand First Coalition Government: 12th October 1996-10th December 1999

National-New Zealand First Coalition Government: 12th October 1996-10th December 1999

Prime Ministers

James Bolger	12th October 1996-8th December 1997
Jenny Shipley	8th December 1997-10th December 1999

Ministers of Health

Bill English	16th December 1996-31st January 1999
Wyatt Creech	31st January 1999-27th November 1999

Health Publications

The Coalition Agreement on Health (1996)

Sustainable Funding Package for the Health and Disability Sector (1998)

Hospital Services Plan: Securing Better Hospital Services Into the Future (1998)

Rural Health Policy: Meeting the Needs of Rural Communities (1999)

The Government's Priorities and Goals for Health and Disability Support Services 2000/01 (1999)

Labour-Alliance Coalition Government: 10th December 1999-15th August 2002

Prime Minister
Helen Clark   10th December 1999-15th August 2002

Minister of Health
Annette King   10th December 1999-15th August 2002

Health Publications

The New Zealand Health Strategy (2000)

The New Zealand Public Health and Disability Act (2000)

The Primary Health Care Strategy (2001)

The New Zealand Disability Strategy: Making a World of Difference: Whakanui Oranga (2001)

Labour-Progressive Coalition Government: 15th August 2002-

Prime Minister
Helen Clark   15th August 2002-

Minister of Health
Annette King   15th August 2002-

Health Publications

Doing Better for New Zealanders: Better Health, Better Participation, Reduced Inequalities (2002)

Disability Support Services: Increasing Participation and Independence (2002)

Implementing the Primary Health Care Strategy in Rural New Zealand (2002)

Reducing Inequalities in Health (2002)

Action Plan for New Zealand Women (2004)

Appendix 2

Structure of the New Zealand Health System 1984-2004

Accident Compensation
Corporation...............………….. 1974-

Area Health Boards................….. 1983-1993

Crown Health Association............ 1993-2000

Crown Health Enterprises............ 1993-1997

Department of Health................. 1900-1993

District Health Boards................ 2001-

Health Care Plans..................... 1991-1993

Health Funding Authority............. 1997-2001

Health Reforms Directorate........... 1991-1993

Ministry of Health................…… 1993-

National Advisory Committee
On Core Health and Disability
Services................................ 1991-1997

National Health Committee........... 1997-

Pharmac………………………….. **1993-**

Primary Health Organisations….. **1996-**

Public Health Commission………. **1992-1994**

Regional Health Authorities….. **1993-1997**

Massey University Campus Human Ethics Committee: Palmerston North (HEC: PN)
Old Main Building, Turitea   Fax: 64 6 350 5622   http://www.massey.ac.nz/~muhec

Professor Sylvia V Rumball, Chair   Secretary
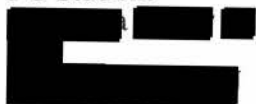Telephone: 64 6 350 5249   Telephone: 64 6 350 5799 extn 7773
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Massey University

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5 June 2003

Ms Susan Mellsopp
PG Student

Dear Sue

Re: HEC: PN Protocol – 03/10
New Zealand's Health Reforms: Their Impact on the Lives and Experiences
of Disabled Rural Women

Thank you for your email dated 10 May 2003 and the amended protocol.

The amendments you have made and explanations you have given now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Campus Human Ethics Committee: Palmerston North for further consideration and approval.

A reminder to include the following statement on all public documents "This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol NO/NO. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz"

Yours sincerely

pp Heer

Professor Sylvia V Rumball, Chair
Massey University Campus Human Ethics Committee: Palmerston North

cc   Professor Robyn Munford, Sociology, Social Policy & Social Work, TURITEA
     Dr Jenny Coleman, Sociology, Social Policy & Social Work, TURITEA

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Massey University Human Ethics Committee
Accredited by the Health Research Council

Te Kunenga ki Pūrehuroa

Inception to Infinity: Massey University's commitment to learning as a life-long journey

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

Advertisement for Research Participants

Are you a disabled woman who lives in a rural area and has contact with the health system?

A Massey University Master's student researching the impact of New Zealand's health reforms on disabled rural women would like to interview you.

If you are interested in taking part in this research please phone(collect)

Susan Mellsopp
Ph█████████ or email me at █████████████

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 03/10. If you have any concerns about the conduct of this project, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V. Rumball@massey.ac.nz

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

The New Zealand Health Reforms: Their Impact on the Lives and Experiences of Disabled Rural Women

Consent Form

THIS CONSENT FORM WILL BE HELD FOR A PERIOD OF FIVE (5) YEARS

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 agree/do not agree to the interview being audio taped.

I agree to participate in this study under the conditions set out in the information sheet.

Signature:……………………………………..Date:………

Full Name-printed……………………………………

Massey University
COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

The New Zealand Health Reforms: Their Impact on the Lives and Experiences of Disabled Rural Women

Information Sheet

My name is Susan Mellsopp and I am currently enrolled at Massey University studying for the degree of Master of Philosophy in Women's Studies. I can be contacted by telephone at ▉▉▉▉▉ by fax at ▉▉▉▉▉ or by email at ▉▉▉▉▉▉

My thesis is being supervised by Dr Jenny Coleman and Professor Robyn Munford at Massey University. They may be contacted by telephone at 063505799 ext. 7880(Jenny Coleman) or ext. 2825(Robyn Munford) or by email; J.D.Coleman@massey.ac.nz and R.E.2.Munford@massey.ac.nz

My research focus is on issues surrounding disability, and to date I have undertaken three research projects; two centred around visual impairment, and one on intellectual disability.

As a rural dweller who is visually impaired I am acutely aware of the many issues which arise when dealing with the medical and emotional needs surrounding disability, often in geographical and social isolation. My experiences as a disabled rural woman have been the central pivot for undertaking this research for my thesis. The contrasting and changing experiences of my life since becoming visually impaired, and the increased realisation that women who live in rural areas and experience disability often receive a lower standard of health care than their urban counterparts has offered me a research challenge. I hope to bring an understanding of the health reforms and their impact on the lives and experiences of disabled rural women to both policy makers and health service providers.

I will be interviewing six women who will be either known to me, introduced by word of mouth, or who will be recruited via advertisements in disability related newsletters and magazines. Two separate telephone interviews will be conducted with each woman between November 2003 and January 2004, each interview will be audio taped and will be approximately 1-2 hours in duration. Some follow up clarification may also be

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necessary as I complete the analysis and writing processes.

I give you my personal assurance that I will protect your anonymity to the best of my ability by the provision of a pseudonym and the removal of information which could identify you. All our discussions and taped interviews will remain confidential. All data and personal information obtained during the taped interviews will be transcribed by the researcher and will then be stored in a password protected computer file and a locked cupboard. All data will be disposed of after 5 years concomitant with the requirements of the Massey University Human Ethics Committee.

Concomitant with the research ethics required by Massey University please note the following.

- You may decline to participate in this research
- You may refuse to answer any particular questions
- You may withdraw from the study at any time
- You may ask for the audio tape to be turned off at any time during the interview

- You may ask questions about the study at any time
- You are providing information on the understanding that your identity will remain confidential and that all discussion between us is confidential unless you choose otherwise.
- At the conclusion of this research you may request a summary of the findings

Thank you for being prepared to take part in the research for my thesis. I, Dr Jenny Coleman or Professor Robyn Munford can answer any queries or concerns you may have, so please feel free to address these to any of us.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol No 03/10. If you have any concerns about the conduct of this project, please contact Professor Sylvia V. Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North. Telephone 06 350 5249, email S.V.Rumball@massey.ac.nz

The Impact of the Health Reforms on Disabled Rural Women

Questionnaire

1. Name:

2. Age: Under 20( ) 20-30( ) 30-40( ) 40-50( ) 50-60( ) Over 60( )

3. Ethnicity

4. What is your highest educational qualification?

5. Are you single, married, in a de-facto relationship, other?

6. What contact do you have with other family members?

7. Please describe briefly your disability?

8. How long have you been disabled?

9. Explain briefly the physical effect your disability has?

10.   What is the nearest town where you can access health services?

11. Which Health Board area do you reside in?

12. What type of health services do you access?

13. Which disability support services do you have contact with?

14. Do you use on a regular basis other medical service providers such as physiotherapists, osteopaths, naturopaths?

15. How did you find out about this research?

16. If you would like to choose your own pseudonym please write this below.

Bibliography

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