EDGES, MARGINS AND ROCKY PERCHES:

LIFE STORIES OF OLDER DISABLED WOMEN

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This is a book (sic) about edges, margins and rocky perches. It is the story[ies] of survival in these outposts as told by the residents: disabled girls and women (Rubin, in Fine & Asch, 1988: ix).

ABSTRACT

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The life stories of older disabled women are explored in this 'insider' study, as a part of dis-covering this marginalised community.

Current images of disabled women, and explanations of how their identity is conceptualised focus principally on one or another factor. But this only provides a partial or static explanations, and laws policies and practices using such concepts as a basis are likely to be less than adequate. A key issue in this study is thus how identity for disabled women, can be adequately conceptualised. An alternative approach of multiplicity, of 'in between' as articulated in writings by Sawicki (1993) and Bhabha (1994) is proposed.

Oral history interviews were conducted with seven disabled women over the age of 60. Methodology was carefully formulated to be appropriate to the situation of this marginalised group. Two central features were consultation with the community of disabled women, and partnership processes used with the women whose lives were audiotaped. Conventional oral history methods were used, with appropriate modifications to technique and technical considerations to ensure accessibility.

The interviews were analysed in terms of the themes emerging from the interviews. The themes are in three main groups. The first grouping is about invisibility, attitudes and effects arising from the attitudes. The second grouping draws out the way disability, gender, age and work were seen to relate to one another. The third grouping is about the way identity is conceived, and how seemingly-discrete parts of identity fit into a whole.

The study has implications for disabled women, and to others for whom identity does not derive solely from one group. The concept of multiple identities is therefore significant to lawmakers, policy formulators, employers and temporal and spiritual leaders.

TABLE OF CONTENTS

Abstract

Acknowledgements

INTRODUCTION

"The philosophers have only <u>interpreted</u> the world in various ways; the point, however, is to <u>change</u> it." (1977: 15). Karl Marx's ringing sentiments were written in the 19th century, but still constitute an excellent reminder to the present that any research is most powerful when it is oriented to change in a tangible manner. But simply to assert that change is required is not enough. To understand what change is needed, the context should also be known. Change is informed by an appraisal of what exists in the present, as shaped by the past. In this thesis, the context, and evaluation of the context that exists for disabled women constitutes a base for the methodology used in the research. The methodology is, in turn, a significant component of the thesis.

This thesis is about stories, about identity, about power, about interconnections and about change. It is about disabled women telling their stories themselves, not having them fitted to some external image, or interpreted by others. It shows how these disabled women make sense of their experiences of their lives. It also challenges assumptions that disabled women fit satisfactorily into a single major image of disability, or female, or age, by developing an approach where the diverse identities within disabled women are acknowledged.

The research arose out of my acquisition of disabilities 15 years ago. I became aware in very concrete ways of the existence of discrimination on the basis of disability. Subsequently I came to see the images of disability both as represented in orthodox fashion, and in a counter-discourse of the socio-political model. But the problem was, in none of the discourses I encountered was there an adequate way of describing the identity of disabled women. My experience, and the experience of other disabled women with whom I talked was that we were bundled up in some category that did not really fit, and we were subject to laws, policies and practices that were inappropriate, because our existence was neither

acknowledged nor adequately responded to. A key purpose of the thesis was to develop ways to bring the experiences of multiplicity, of being 'in between' forward at experiential, theoretical and concrete levels.

One sequel to disability was that I more closely examined the community of disabled women in Aotearoa /New Zealand, and realised that we constituted a distinctive, but unacknowledged entity. There has been an absence of the stories of the experiences of disabled women, as articulated by ourselves. Some well-intentioned people had written about us, even written down our stories for us. But the written down stories were not us, telling ourselves, speaking our own words for ourselves without interpreters, and telling our own experiences. Many disabled women did not know the stories from one another's life. The telling by others highlighted that our own experiences, our expertise about ourselves was not recognised or affirmed.

As a disabled woman, I was aware that our stories were not available to one another and that making them present would aid the process of recognition by disabled women of our shared voices. To enable the telling of our stories, our experiences in our own voices on to audiotapes would be one part of the recognition. It would also illuminate identity for disabled women, showing the complexities within the identity, which were not addressed in law, policy or practice.

So in a sense, the research question was already 'there', and it was a matter of it becoming evident to me. I began with the problems of identity for disabled women, where lack of recognition and acknowledgment of disabled women meant inadequate laws, policies and practices. These, alongside the need for disabled women to tell their life stories in their own voices formed into a potential project to audiotape oral histories of disabled women. It further became apparent that I should record the stories of older (60 years or more) disabled women, so as to

begin a record of our stories with the more distant memories, before the memories of events were lost.

When I raised this possible research project within the community of disabled women as a whole, there was a strongly positive response, both for the question, and for the research being conducted by a disabled woman. As a member of this community, I shared the experience of disability and of discrimination, and they were clear that this experience should be a key element to such a project. Between us, we recognised that work was a key focus in the lives of disabled women, and work became the last component of the research question: what are the experiences of older disabled women, particularly in relation to work in its wide sense of purposive activity which gives meaning in the daily lives of most adults.

Disability, gender and age are all identities within an overall identity, but work is not an identity. Rather it is a central component of the lives of disabled women, just as it is central in the lives of non-disabled women. It is the locus of a lot of the discrimination encountered by disabled women, and it carries many of the messages which influence a sense of identity. The stories of the disabled women I interviewed show numerous instances of work influencing identity.

I approached the task of translating the research question into methods with two focuses: partnerships and change. The process was, in itself, a vehicle for change, since it modelled partnership in research. The change in working relationships between the parties to the research could be seen to constitute challenge to conventional relationships of research production. It also implicitly offered changed perceptions to disabled women, who were interviewed. Through the action of telling stories, a re-evaluation of the meaning of experiences for individual was possible. In having the stories available to the community of disabled women as a whole, it offers the possibility of change to others' perceptions. The life stories, and the contextual material can constitute a platform

for critical evaluation or re-evaluation of the meanings disabled women give to their identities: how they theorise disability, and the strategies they adopt towards change to legislation, policies and practices.

There are two outcomes of the research. First, it comprises a tool for disabled women to instigate change at a societal level. The change is also possible in academic theorisings about disability, and about identity. The second outcome is the inception of an archive of the life stories of disabled women in Aotearoa/New Zealand. The archive will be stored at the National Oral History Centre of the Alexander Turnbull Library.

Words do Move Us

In this thesis, my use of language to refer to disability varies between two phrases: 'disabled women' and 'women with disabilities'. In this thesis, I argue for the power of thoughts and words. In common with those who argue for socio-political models of disability (for example Oliver 1996), I do not deny that the way states of being are named can shape them. But I will argue in this thesis that both 'woman' and 'disabled' are identities within an overall identity, and neither has primary importance. I have therefore used both phrases, rather than one, to signify that one, or other identity has 'first place'.

Thesis: Outline and Format

In the first part of this thesis there are four chapters. The first three chapters comprise a review of literature. The first chapter shows the connection between thoughts about disability and attitudes, and concrete actions in Western society. I show the development of a dominant discourse about disability that has taken place over history and occurred in a series of identifiable and mutually reinforcing stages. In the second chapter I examine the current social context in sections relating to the key themes of disability, gender, age and work. Issues that are significant to each group are discussed, as are the similarities and differences

between the groups. In the third chapter, I discuss issues of identity and power. The third chapter arises out of the literature in the first and second chapters, where I have pointed to the limitations of unitary or dualistic conceptions of identity, in the lives of disabled women, and the impact of power. Drawing from the theories of postmodern writers on multiple and concurrent identities, notably Sawicki (1992) and Bhabha (1994), I advance an alternative approach to conceptualising identity for disabled women. In this approach, change to relationships of power, and challenge to the dominant discourse are potential outcomes.

The fourth chapter describes the methodology I used in this research project. It begins with an examination of key components in development of methodology: theory, methods, relations of power and values. I then discuss ethical issues, particularly consent. An examination of research methods and appropriate practice follows. It considers the difficulties that conventional relations of power in research production impose, then leads to a specific consideration of the methods chosen. Here I describe the techniques and processes I used, which have been chosen to be consistent with my objectives of partnership and the contribution of tools for change. I then preview the themes which have arisen from the interviews, which are discussed in Part Three. At the close of this chapter, I reflect on the process issues which arose during the interviews, pointing to what they have to say about methodology and ethics.

Part Two of the thesis presents the narratives of each of the seven women with disabilities who I interviewed. I have used the content of each disabled woman's story, so that the narratives are accurate, and correspond with the actual experiences recorded rather than interpretation. In addition the narratives have been shaped so that they convey a sense of each woman's individuality. The connections between the story, the way in which it is told, and the individual who 'carries' the story is reinforced.

In Part Three, I analyse and discuss the narratives. I return first to the connections between thought, attitudes and concrete consequences, to give a historical overview of disability in Aotearoa/New Zealand. This section gives a setting for the stories. It also serves to give background to the analysis and discussion which follows. In this section, the themes which emerge are generally consistent with trends in the literature of the first section. A first grouping deals with invisibility, attitudes and expectations, then the consequences of these three themes. A second grouping is about how disability, gender, age and work are seen by the disabled women, and how these components interlink, or diverge from one another. A third grouping is about a sense of identity. The conclusion evaluates the research project, identifying strengths and limitations, and what implications it raises.

Ideas, words and material conditions-some preliminary observations

I have proceeded from a basic understanding of the way in which ideas, words and material conditions relate to one another. Since this understanding is basic to the subsequent chapters, I shall first clarify the relationships between thoughts and material conditions.

Those of us who are disabled all reach and re-evolve individual, and greatly varying understandings of what our disability means to us. One such understanding is articulated by Maria Jastrzebska (1994). She says:

If I can live with this dilemma

It doesn't seem too much

To ask others to recognise

How I'm different

But very ordinary

Ordinary and very different

(1994:153)

This is the single understanding of one individual and at one point in time: one of the multiplicity of the ways we make meanings from our lives. However, meanings go beyond how just one individual or group understands itself. They also indicate how others understand and describe the group, or its constituent individuals, and signal the bases these varying parties use to explain their existence, or experiences. They are about who gets to say what about whom, and about the consequences of the commonly-accepted understandings, or discourses. The understandings are, in short, about power relationships.

Foucault (1965) analyses the way others define how a group 'is', and what happens as a consequence of the definition. His analysis of how madness has been defined, then treated by others illustrates how words and tangible consequences are linked. The sequence can be applied to disability. In the third chapter the precise mechanism of this process of discourse and what it means in relation to power is discussed. I also draw out the concrete implications of other-definition: what happens when power is 'done' to a disabled person.

The sequence I argue for, of ideas, words, then practical consequences, is by no means universally agreed. One significant basis for explaining disability is material circumstances, or the way external factors like social and economic status, or the way a society is organised creates disability as a state of inequality. British socio-political analyses of disability draw from the materialist analysis developed by Marx and Engels. The analysis asserts that actual social conditions are a consequence of material conditions within a society, and out of this, oppressive attitudes and behaviours emerge.

Oliver (1990, 1996) shows how this perspective can be applied to constructions of disability. He discusses the development of a capitalist economy where changes meant that "disabled people came to be regarded as a social and educational

problem" (1990: 28). This, he says, is in contrast to the attitudes of the pre-industrialised era in which people with disabilities were able to participate and contribute, and were not segregated from the rest of society. From this basis of historical materialism, he then develops a social model of disability, in which the condition of oppression for disabled people is best attended to by changes to the material conditions of society.

The argument is clearly articulated, but the historical basis upon which it rests is capable of alternative readings. In this thesis I argue that the ideas we have about what disability means, how we theorise it and the concrete consequences of thought, are given insufficient attention in a materialist perspective.

In order to give words and thoughts proper recognition and support my contention, I draw from post-modern theories to highlight how thoughts, manifested in words, shape the realities we, as disabled people live. In asserting this sequence, I would not deny the accuracy and impact of a large volume of work that details the negative material circumstances of disabled people and the negative societal positions, for example Abberley (1993), Morris (1991, 1996), Oliver (1990, 1996), Fine and Asch (1988). Rather, I argue that to theorise about the oppression of disability as arising primarily from material circumstances is less than adequate. Such use of one single explanation, which has been described as grand theory (McNay 1992), sits poorly with post-modern explanations. I argue that words, thoughts and material circumstances are by no means mutually incompatible, but I propose a more realistic synthesis of thoughts, words and material circumstances.

Debate is clearly not concluded on the respective merits of ideas and material circumstances. Barnes (1991) supports further debate, and comments "It would not be possible to confront this problem without being involved in political debate and taking up positions on a wide range of issues" (1991: 233).

From thoughts to actions

The defining of one group by another, a recurring theme of Foucault's works[1], happens, in the first instance, via ideas and words. Okri (1996) captures the elusive power that words and ideas have over us when he says:

> Words do collect in us anyway. They collect in the blood, in the soul, and transform or poison people's lives...we seem to think that words aren't things....But then, it is possible that we know all too well the awesome power of words, which is why we use them with such deadly and accurate cruelty. (1996, 4.)

We put words, whether in a conscious or unconscious way into theories, which make sense of what is happening or existing. Theories constitute a platform from which material is organised, analysed and reflected on, but they are not unchanging and ever-certain. Appiah (1991) describes theories as dynamic entities which are likely to be modified or added to. He asserts that they are both part of the being and part of the doing: about living in particular ways, rather than just seeing the world in different ways. Thus, he describes a flexible situation where "there can be many such 'exhaustive and definitive' practices, each adequate to the degree that any theoretical practice can be adequate to its own constitutive project" (1991: 84). While the use of theory and practice as interchangeable terms may be questioned, few writers would deny that they are linked, that the words of theories are used to have real, tangible consequences. They translate into attitudes and behaviours which then inform policies practices and laws.

An example of this is seen in the recent review which Schick (1996) conducted of the impact of reforms to the New Zealand Public Service since the 1988 State Sector Act. In his report he traces the practices which grew from the base of a

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[1] In Foucault's works , the relationship between knowledge power and truth is repeated often. The most clear expositions on this relationship are seen in *Discipline and Punish* (1977) and *The History of Sexuality* Volume 1 (1978)

libertarian ideology, pointing out how two very different practices of managerialism and contractualism[2] grew out of a single ideological base. The practices, which have distinctively different consequences derive from a single assumption about the motivations of humans towards self-maximising behaviours that increase pleasure and profit.

The example shows a sequence from thoughts and assumptions to theories, then to policy and practice, shaping the actual conditions in which humans exist. I contend that a similar process has occurred to women with disabilities, informing law policy and practice in a substantive way, and effectively blocking the experience of ordinary living from disabled women. I describe the process in relation to disability in the succeeding chapters.

In this thesis, I argue that alternative approaches to disability could be of as much use, and query the ongoing applicability of a solely materialist analysis to the lives of disabled women. Instead I look to the way in which discourses,[3] or sets of ideas about disability, women and age fit, or do not fit together, to speak with more conviction. To begin an exploration of this topic, I turn, in the first chapter, to the way in which thoughts and actions have been seen to interconnect in a Western discourse on disability, and to the impact of thoughts, images and action about identity for, but not conceived by disabled women.

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[2] The contrasting thrusts of these two strands was encapsulated by John Martin, in a speech to a seminar on the Schick report (5 December 1996, Wellington) as the "let them manage" freedom of managerialism, versus the "make them manage" sense of minimising exploitation of contractualism

[3] Sets of communication acts which are also "a process of creating social meaning" (Eagleton 1983: 115). They carry an implication of what 'truth' is and who has the power to say it.

PART ONE

CONSTRUCTIONS OF DISABILITY: THOUGHT BECOMES PRACTICE

This chapter traces how, over time, thoughts about disability interactions have related to the laws, policies and practices of the period. I show how such interactions take place in a succession of phases, which overlap, and are consistent with one another. Their additive effect on the images of disability is thus particularly strong. What this section outlines is the development of a dominant discourse about disability. It is important to consider the discourse for two related reasons.

First, there is need to give better context to the lives disabled women have lived, because the lives are strongly influenced by what is thought and done about disability. In subsequent chapters I will develop my argument that there are multiple influences on the identities of older women with disabilities, providing concrete examples of this influence in law, policy and practice, and especially in relation to work. At this point, however, I have chosen to focus on the development of a discourse about disability.

Second, it is important to appreciate the extent to which disability has been defined by others. The conventional images of disability can be seen to convey a 'truth' about what a disabled identity really is. This stance is rejected by many post modernists. Eagleton (1991) points out that there is no "privileged epistemological language that can allow us untroubled access to the 'real'" (1991: 202). Similarly McLaren (1993) argues that "identities cannot be fixed within closed systems of meaning....there are no true identities, only identities that are open to inscription, articulation and interpretation"(1993: 212). Such comments challenge conventional readings of disability, hence a critical evaluation of how thought and action have interrelated in disability history is necessary.

Disability has always been an aspect of human existence, although not in any well-recognised position[4]. It is a state of being that has not always been called disability, nor has the term used always encompassed the same constituent entities, either across history or across culture. In this century, for example, people with more severe disabilities are more evident, because they live longer, and there are many more people disabled by the technologies of war such as land mines or economic conditions of poverty that limit the development of adequate medical regimes in the Third World (Oliver, 1996).

Further, there are ongoing definitional debates about disability as various parties debate where conditions such as asthma, deafness, autism or Alzheimers disease 'belong'. Although disability has been acknowledged in a variety of ways, just as it has been constituted in a variety of ways, the acknowledgment is much more consistent, in being negative. Acclamation is very rare; ignorance, dismay or disgust is common.

This chapter therefore addresses these negative images of disability in exploring how negative social attitudes and consructions of disability have translated into law, policy and practice. I highlight four major and mutually reinforcing influences in the historical development of a discourse about disability: spiritual notions, Poor Laws, Utilitarianism and Medical Model thought.

Explanations of disability, which differ over time, may have spiritual or philosophical bases, and be manifested in particular social or cultural settings. In this section, I focus on two specific settings for thought and action: Western attitudes to disability and Maori attitudes to disability. Both are relevant to the location of this research in Aotearoa/New Zealand. It is noted here that the Western-thought predominance in disability is consistent with the overall

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[4] Barnes' (1996) compilation of references to disabled people at various periods in history, including prehistoric, reflects the scanty nature of the material available. He also outlines how disability has been seen, and treated, in different ways by different cultures.

dominance of Western thoughts and preferences that occurred in the colonisation process. But in-depth discussion of reasons why Western attitudes to disability have predominated over Maori concepts needs to take place in another, more appropriate, arena.

In Body And In Spirit: Spiritual Dimensions

Western attitudes to disability have been closely bound up with spiritual explanations. Indeed, church and belief were central to everyday life throughout most of the preceding centuries and in most of the known Western world. The influence of spirituality on disability is unsurprising. Both Judaism and Christianity opted for stern, punishment-focussed theologies. Although writings from both old and new testaments of the Bible can be selectively read, most interpretations have concerned themselves with negative injunctions, and punishment for transgressions whether intentional or not[5]. Writings by early Christian 'fathers' such as Origen Gregory or Augustine explored sins and deficits exhaustively. The God one must worship would punish for all manner of sins, as individuals strived to attain a state of grace.

By Medieval times, church services could tell an individual that their disability represented a very great and punishable deficit[6]: "thou hast great grace at the hands of Our Lord, that he desireth to punish thee for thy iniquities in this world" (cited in Foucault 1965: 6). The assumption was that disability was culpable. Redemption might be sought through spiritual channels, but actual bodily 'relief' of needs such as food, clothing or shelter received lesser attention. Too much attention to such 'carnal' (bodily) needs would detract from the primary goal of spiritual salvation. Charity, in the form of almsgiving was cautiously approved of by spiritual leaders, however.

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[5] Representative of this orientation is the Old Testament book of Deuteronomy, which includes rules about worship practices, sexual practices, punishments for crimes and dietary restrictions.

[6] This ca. 13th century church ritual is from the Church of Vienne. In this particular service, the 'iniquity' is leprosy.

Poor Laws

Because church and state were, for many centuries, closely interrelated[7], the laws of the state too reflected a stern mindset. An English statute of 1349 forbids the giving of alms "if it is possible for the individual to work" (cited in Stone, 1984: 35). Lawmakers also suspected the 'true' physical state of a disabled individual. An English statute of 1530 describes vagrants who use "divers and subtle crafty and unlawful games and plays" to feign illness or disability (ibid: 32). Disability seemed to be an optional condition, associated with devious practices and unruly attitudes.

The suspicion also came about because disability was part of a non-differentiated bundle of 'the other'. These were the people who, for various reasons were not part of the usual run of life. They might be wandering beggars, outlaws, pedlars, ex soldiers or women cast out from their homes. Such 'others' did not conform to the norm. They might, indeed be seen as a threat to established order, so that states often used restrictive enactments to deal with the threat they were seen to represent. In European states these enactments were known collectively as Poor Laws.

To disabled people, the enactments probably added little comfort to their existence. Conventional history records a change from an agrarian based economy where small scale and cooperative systems of work could exist, to an economy with a manufacturing base, urban-sited factories and individualistic patterns of work. The change was particularly disadvantageous to disabled people, and as a consequence, they were less easily able to fit into conventional norms of community and work. (Oliver, 1990). In such situations, it was easy to see them as 'the other', since they did not fit readily into the new framework of work as potential workers.

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[7] Kings, queens or other rulers were usually heads of the church in that country

Stone (1984) describes Poor Laws in England from 1500 on as reinforcing "salvation" through individual effort, even though the link between church and state was no longer explicit. Arguably the most lasting images of the Poor Laws are the institutions they gave rise to. In Lyons or Paris, they were the houses of confinement. Hamburg, Breslau or Leipzig had houses of correction and Bristol, London or Oxford had workhouses. In these buildings, inmates led grim existences: harsh attitudes and harsh conditions existed. Workhouses existed in varied forms over the next 400 years.

A trend away from religious domination of secular government developed, and became gradually more influential through the 15th to 18th centuries. Freedom from religious orthodoxy came through the struggles of people such as Gallileo, Anne Conway[8] and Martin Luther[9]. In turn, their struggles aided the rise of other philosophical thought, particularly the Utilitarianism of Bentham and Mill.

Rational and Philosophical Influences

Utilitarian philosophy focuses on the freedom of development of each individual that is necessary so that all can attain free development (Duncan, 1973). It further avers that people are principally motivated by their own self interest, so that they maximise pleasure and minimise pain. So when people pursue their own self interest, they should do so with a maximum of freedom, and the consequence is that a pursuit of self interest enables freedom of development for all. In other words, self interest is in the best interests of all.

The concept of self-interest had certain significant limits. Humanity is also seen to have a tendency to what Malthus calls "natural indolence" (1970: 245). In this state

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[8] A highly respected and influential contemporary of Thomas Moore, Renee Descartes and Gottfried Liebinz, Ann Conway's natural philosophy attempted to bring together material and spiritual worlds. (Alic, 1986:5)

[9] Martin Luther dared to publicly articulate unorthodox theology when conformity with spiritual thought was highly desirable. His ability to conceive of ideas that were counter to conventions had limits, however and he was rigid and harsh in his attitudes to disability. He said he saw the devil in severely impaired children, and recommended killing them (Shearer, 1981: 77).

of indolence, Malthus believes that cheating or idle means of furthering self interest are used. The consequence is that some other individual needs to put in extra self exertion to make up the deficit. Thus, Utilitarianism implies equal and constant effort from all. To those who did not appear willing, for whatever reason, and regardless of the setting, to contribute their "fair share", there were negative sanctions. Poor Laws were good reinforcers of Utilitarian notions of rationality, enforcing contribution of this "fair share".

The concern that any relief which could be obtained through Poor Laws went only to people who were eligible for it was a key preoccupation of those who administered the legislation. Eligibility remained a key concept, and there were a variety of processes by which it was assessed. Throughout the centuries, ever-more complex methods of assessment were used by government functionaries who administered the enactments and laws. Acquaintances and neighbours were questioned, the individual would be closely interrogated, tests of willingness to work and home visits were all regularly used methods (Stone, 1984). However a satisfactory and definitive measure of eligibility was elusive.

Through use of these techniques, administrators began to recognise, to some rudimentary extent, that some of 'the other' were truly unable to work be they ever so willing. Further categorisation of this group of "deserving poor" meant that by 1834, Poor Law administrators recognised five categories of pauperism. These were children, the sick, the insane, defectives, and the aged and infirm (ibid: 106). The four last of these categories would broadly be recognised as disability.

In overall terms, three centuries of Poor Laws meant little change to concepts of disability: it remained on the edges of normality. Occasionally a disabled individual would participate in a comfortable, even prestigious life. But it was more by chance than through a general attitude of acceptance. For most disabled people, Utilitarianism brought little improvement to either thought or material

circumstances. While the philosophy was still influential, a further major influence in the form of medicine began to come to coalesce into the features which would give it such impact on disability.

Medical Models: The Rise of Medical Science

Throughout the previous centuries, medicine has had consistent themes of healing from something wrong, deviation from moral or spiritual rectitude, and the need to explore, classify and treat (Alic, 1985). The exploration, and success of the treatments has varied considerably, but the basis of medical practice has remained focussed on an individual, following a course from manifestation to cure (Bury, 1986).

An approach of scientific enquiry began to gather momentum from late 18th century, through individuals such as Lady Mary Wortley Montague, Koch and Pasteur. They brought ordered approaches to treatment of medical conditions and identified microbes. When, in the 19th century, a scientific approach spread further into medicine, stethoscopes, laryngoscopes microscopes and ophthalmoscopes were developed and doctors were able to use them to differentiate, diagnose and treat more accurately.

The emergence of medical advances in the 19th century proved to be advantageous to Poor Laws. The advances in detection and differentiation of conditions it brought gave a reliable means to categorise with more accuracy. To be able to rely on some external measure, such as medical science offered, was very useful to administrators. It responded to their ongoing concerns about cheating and malingering. It brought status too. In many Western countries, particularly the United States of America, physicians became part of the administrative structures now growing up to assess and legitimate disability. Stone (1984) asserts the role of physicians in sorting out 'real' from 'feigned' disability was filled with considerable reluctance. Physicians felt "disability certification was

not a task the profession wanted to assume...the adoption of a certifying role would only create enormous tensions between doctors and their patients" (1984: 112) However Stone also acknowledges that this particular way of putting policy into operation involved contradictions, as some understandings of disability were systematically included, while other understandings were systematically excluded.

While physicians fulfilled this certificating role, and continued to diagnose and to treat in ever-increasing degrees of specificity, the impact of medical models was reinforced through the insights of psychology. As it developed from late in the 19th century, psychology focussed at an individual level and it's orientation to disability was on a 'problem', an individual deficit, a state that was innately less than normal. An initial position describes the presence of disability as inherently damaging to the individual's personality, and requiring 'adjustment' (see Shindi, 1983, or Kasprzyk, 1983). Later insights (for example Chesler, 1972 or Goffman, 1968) saw negative social encapsulations of disability-as-deviance as a seemingly unalterable response to disability. Since the individual had an ongoing problem, there would be little likelihood of change to the situation.

The pattern of thought whereby the problem is located within the perceived deficits of the individual is consistent with the previous influences. The element of censoriousness in religious and Utilitarian approaches is reinforced by the deficit or individual tragedy orientation of psychological thought. Psychological thought added to a discourse about disability that remained negative over a number of centuries, and it was a complement to 'scientific' thought in medicine. Oliver (1990) encapsulates the combination of medical technology and psychology as a "personal tragedy theory" (1990:1) of disability. In it, the assumptions are laced with loss, being less, and the unacceptable difference in the other, the face of the stranger. In writing about facial disfigurement, Grealy (1994), captures the essence of this perception of negative difference, of individual 'less-ness' when she says:

Society is no help. It tells us again and again that we can most be ourselves by acting and looking like someone else, only to leave our original faces behind to turn into ghosts that will inevitably resent and haunt us. (1994: 222)

Socio-political models

Control of disability through the policies and practices accompanying the medical model was, and is pervasive. Medical criteria and medical personnel have featured largely in the lives of disabled people to assess, rehabilitate and act as gatekeepers of goods and services such as hearing aids or personal carers. But such a discourse has come under question. Critique of thought and practice of the medical model, developed over the last 30-odd years, has been articulated by many disabled analysts such as Oliver (1990) who writes:

> That disability has become medicalised there can be no doubt. Doctors are centrally involved in the lives of disabled people....Some of these involvements are entirely appropriate....But doctors are also involved in assessing driving ability, prescribing wheelchairs, determining the allocation of financial benefits, selecting educational provision and determining work capabilities and potential. (1990: 48)

This critique has gone beyond pointing to deficits of both thought and action of medical models-it has also seen the development of alternative concepts of disability, in the form of socio-political models[10]. Such models contain ideas about disability that are in direct challenge and contradiction to those which have grown over preceding centuries. Gadacz (1994) comments that "one of the strategies...has been to try to reinterpret the meaning of disability by constructing

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[10] It has been common practice among disabled people to use the term 'the social (or medical) model', which has caused some difficulty to (principally) non -disabled commentators. They rightly point to a number of variants within a socio-political model. The use of the singular term is a convenient convention: few disabled people believe that a single unitary medical model exists, but this point has been imperfectly understood by some non-disabled people.

normative definitions of disability are built" (1994: 9). Within the overall socio-political model, two interrelated approaches are apparent. They are based around approaches to the socio-political model that are British or American.

British Approaches

British approaches to the socio-political model have largely grown from the materialist theories of Marx and Engels. The materialist argument is that the way a society is constructed-its actual material circumstances- advantages   certain groups and oppresses other groups. Such critique has largely grown out of disabled people themselves. An example of both of the above aspects is the 1976 Statement Of Fundamental Principles, in which the authors, the Union of Physically Impaired Against Segregation (UPIAS) says:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society... we define impairment as lacking all or part of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which...excludes them from participation in the mainstream of social activities. (Cited in Oliver, 1996: 22).

The involvement of disabled people in this analysis has been an ongoing feature of British approaches. A second feature is the overwhelming use of a single theoretical orientation. Writers from Hunt (1966) [11] through Finklestein (1980) Morris (1990) and Oliver (1996) maintain an analysis that is predominantly materialist, although focussed firmly on disability.

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people believe that a single unitary medical model exists, but this point has been imperfectly understood by some non-disabled people.

[11] Hunt's actions in the 1970s in publicly soliciting discussion from other disabled people led to the inception of UPIAS, which was one of the first disability rights movements in England.

American Approaches

By contrast, American critique has come from more diverse roots. In functionalist approaches to sociology, there was questioning of the social implications of what were seen to be ' medical problems' (Bickenbach, 1993) and development of a concept of stigma, a process of marking out and setting aside[12] (Ainsley, Becker and Coleman, 1986).

A further influence was in the black civil rights movements. Individuals both within and outside the movement saw that the denial of rights to black people was the same phenomenon that was happening to disabled people. They sought to apply principles of self-determination and control for all citizens, and began to argue for civil, political and social rights. As in Britain, disabled people such as Hahn (1988) and Asch (1988) were in the lead of challenge to the orthodox patterns of thought and practice.

Assessing Socio-political Models

Socio-political models may be criticised for their rigid and unitary nature. For example French (1993) describes a tyranny of 'correct' views on the social model, and Morris (1991) expresses concern for diversity within disability when some:

> Think they are addressing such interests by highlighting how much worse off disabled women are than disabled men (and how much worse off black disabled people are than white disabled people)....We too must not fall into the same trap of treating issues around women and disability, race and disability, sexuality and disability (or indeed class and disability) as something to be 'added on'. (1991: 179)

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[12] The use of this (originally Greek) concept in relation to disability was developed by Goffman (1963).

In these words Morris highlights a central concern of this thesis: finding an adequate way to deal with what one disabled activist calls "all the bits" [13]. That is, conceptualising identity in a way that deals adequately with all the identities that comprise an individual's total identity.

The focus of socio-political models has been largely on the extent to which material circumstances of a disabling society have resulted in disadvantage to disabled people, although it has also been concerned to trace some of the consequences of inimical thought. While the critique of socio-political models has been of considerable value, the extent to which it articulates a well developed theoretical basis for change is open to question, and discussion on this is pursued through other channels.

The purpose of showing alternative models of disability here is to highlight the existence of an alternative discourse about disability where different patterns of thought mean different actions. But it is clearly still an alternative discourse, and its lesser status contrasts with the way the dominant discourse has become embedded in policy and practice over the centuries, establishing an effective hegemony.

The overview of this chapter, traces the development of a discourse about disability in terms of Western traditions. The thought patterns of this discourse came with European colonists in Aotearoa/NZ, and like many other aspects of European life, became predominant. But Maori conceptualised disability very differently from Pakeha, though the spiritual and cultural bases to the discourses are not dissimilar.

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[13] Private conversation with the author, May 1996.

Maori Concepts of Disability

A Maori concept of disability is less direct and distinct than Western concepts, and is embedded in a holistic understanding of health. Durie (1984) contrasts Western and Maori perspectives on health. He describes three aspects to Western concepts- physical, mental and social aspects- with emphasis and attention almost entirely on the physical body. He shows four aspects to Maori concepts: taha wairua (spiritual), taha hinengaro (psychic), taha tinana (body), and taha whanau (family). Maori approaches assume an integration of spiritual dimension with those of body and mind, with that integration taking place in the context of wide reaching kinship and community bonds. The effect, then, of this is that the "components blend to form an integrated and comprehensive model for health" (ibid: 2).

It is difficult to trace any distinct, discrete articulation of a body of Maori thought about, or concepts of disability. However, two particular concepts within health are relevant. The first, and arguably the most significant, is an overall focus on waiora, or total wellbeing in the person's tuakiri (total being). Ihi (1996) details the aspects which add up to waiora as: wairua (spirit), tinana (body), hinengaro (mind), whanau (family and whakapapa), mauri (life force), iho matua (spiritual relationship of the person with people, things and the total environment), ngakau (the heart as it relates to emotional wellbeing), whatumanawa (the emotions of a person, and their effect on decision making), pumanawa (potential) auaha (creativity) and tapu (sacredness).

Waiora implies wholeness. It also carries notions of balance to the way constituent aspects make up the whole of waiora. Thus an individual with a disability may have the constituent aspects of waiora in different proportions from one who is non-disabled, but a sense of 'whole' is present in both (ibid: 5). One of the aspects of waiora, pumanawa, is the second important concept, and provides a more rounded-out understanding. Pumanawa implies recognition of the differences

arising from states such as disability, and that recognition and respect are the right of all people. Thus disability does not innately imply an inferior status.

This orientation of mind translates to attitudes and behaviours. In Bevan-Brown's (1994) research on Maori attitudes to Maori with intellectual disability, respondents most often reported stories that illustrated recognition, respect and inclusion. The words of one respondent encapsulate both pumanawa and waiora in saying:

> They are people, and to me, they have just as much mana, if you like, as individuals as anyone else. Now that mana may not be as enhanced in ways through their experience and through what they can do, but, I mean, it doesn't matter, they are people. So with that attitude, I welcome them as being part of the community rather than being apart from it. (1994: 209)

It is hard to find record of the way that ideas of disability, as are implicit in pumanawa and waiora, were or were not manifest in pre-colonial Maori society. Few of the publications which deal with the lore of the past such as Beattie and Tikao (1939) or Makeriti, (1938) refer to disability, even in passing. Post colonisation, written references to Maori attitudes about disability are still scarce. There are occasional actual references to disabled Maori, but they are largely from European sources, and do little beyond attesting to an actual presence[14]. This 'absence' is not unexpected. Barnes (1996) points out that disability is present in societies throughout history, but that it is not usually valued, and so is not mentioned in the society's records, whether these be oral or written.

Western and Maori approaches to disability have evolved very differently, and still display marked differences that will ensure ongoing difficulties in policy and practice that is inclusive. The difference is not just in two directions however:

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[14] For example, in Scott (1975) records that William Fox, sometime New Zealand premier, adopted a Maori child following the slaying of his family by soldiers Fox was commanding in 1875. He cites the Hawera Star's (15.8.1918) report about the incident "it was not true that there were two children killed. There was only one-and he was a cripple"(1975:32).

Maori thought about disability also sits awkwardly in relation to socio-political approaches to disability. Socio-political models look to a recognition of disability as distinct, societally engendered, and with disadvantage imposed through non-disabled mechanisms (see Oliver 1990, Barton, 1996). Such models also emphasise disability as a distinctive entity. However, Maori thought about disability rejects medical models of disability, and there are few approaches to the socio-political model and what it could mean. For instance, who leads the debate on what it means to be a Maori with disabilities: Maori without disabilities or Maori with disabilities?

The lack of debate on this issue makes it inadvisable to speculate, but it raises issues of identity, of what it is to be disabled and at the same time part of another world, which has its own set of imperatives: Maori or female or Pacific Islands or gay or lesbian or old, and so on. The debate needs to progress, if development of Maori and disability issues is to be further addressed. The issues of identity that this particular issue raises will be echoed in the following chapter, while issues of identity are addressed in more detail in the third section.

KEY THEMES: CURRENT SOCIAL CONTEXT

The first chapter shows how the circumstances in which older women with disabilities live currently are greatly influenced by historical practices which in turn arise from thought. I have examined this in relation to disability. But older disabled women have influences from factors other than disability impacting on them, and if identity is to be adequately addressed these factors should be considered.

This chapter considers the key factors that influence being an older disabled woman. I will examine each of four key themes: disability, gender, age and work in turn, and in relation to current circumstances. The chapter is divided into five sections, each corresponding to a separate theme, where the distinctive issues and features are highlighted. In the final section, I discuss the gaps, overlaps and similarities and differences among disability, gender, age and work.

1. DISABILITY

Images, Indicators, Consequences

Images can be seen to convey a 'truth' about an individual's identity as a member of some group: for example about a disabled identity. Such a position is rejected in post-modern thought: McLaren (1993) argues that "there are no true identities, only identities that are open to inscription, articulation and interpretation" (1993: 212). But a more usual practice is to use stereotypes where a series of images encapsulate and enclose all members of a group. Through such a sequence of stereotyping , generalisations are embedded and, for example, all Asians may be seen as inscrutable, or all disabled people lead tragic lives.

Disability has its stereotyped images perpetuated in print, film and other performance arts. A list compiled by Morris (1991) contains current images, such as:

That we [disabled people] feel ugly, inadequate and ashamed of our disability.... That we crave to be 'normal' and 'whole' ...That we desire to emulate and achieve normal behaviour and appearance in all things. (1991: 19-20)

Western literature provides a range of negative images, ranging from the dependence of Laura Wingfield[15] to the 'twisted body, twisted mind' of Dr No[16], or Captain Hook in "Treasure Island" (Kent, 1986). Television and cinema have disabled characters such as Mr Magoo, or Arkwright[17] inciting derision, while Disney re-adaptations, such as the hunchback of Notre Dame re-package disabled characters into cute pitiable morality lessons.

Advertising images are consistent with this approach. Drake (1996) describes the images of disabled people used by charities to solicit financial support as harmful or "deleterious" (1996: 154). While there is some awareness of the negative effect of disability in advertising. Hevey (1992) believes such attempts to remedy the situation will have "promised much but delivered nothing" (1992: 10).

To many disabled people, images continue to show disability in negative and inaccurate terms. In challenge to these images, disabled artists and performers such as David Hevey, Johnny Crescendo and Liz Crowe, (and in Aotearoa/New Zealand, Phillip Patston and Sandra Taylor) operate from a basis of support for alternative, and positive images of disability.

While socio-political theory has been genesis for alternative disability images, some find the alternative less than inclusive. One woman with disabilities describes the 'new' disability image as: "white, male, verbal, middle class, and uses a wheelchair" (personal conversation, 1993). White, bearded, heterosexual

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[15] In Tennessee Williams' play, "The Glass Menagerie"
[16] In Ian Fleming's spy thriller "Goldfinger".
[17] Character in the Ronnie Barker television series " Open All Hours"

wheelchair user "Trapper John"[18] does not show the only actual image of disability, but his is almost the only one used. Many disabled women, for example, Maori, older, poor, lesbian, with communication or other impairments that do not involve using a wheelchair, find it difficult to identify with such a circumscribed image of disability. Busia (1993) describes a similarly restricted situation for black feminists who struggle to express their diversity as black women:

> The issue for us is not of being always *against* whiteness, or *against* maleness....At the same time, we are not interested in finding a mega-theory to create *the* story of *the* Black woman, so much as to sustain ourselves and give voice to our many different voices. (1993: 291)

The key issue though, is that current images of disability, be they traditional tragedy or androcentric alternatives, do not adequately reflect the realities of disabled people, and still arise from external understandings.

A consequence of negative images is invisibility. Le Compte (1993) describes a relationship between invisibility and power: "That their lives are defined as silenced implies that the individuals involved have been deprived of voice without their consent" (1993: 10). Decisions over law, policy and practice about disability regularly occur in the absence of disabled participation. For example, when New Zealand's Human Rights Commission Act was passed in 1977, disability was not included, because non-disabled bureaucrats and politicians decided, unilaterally, that it was not a necessary protection for disabled people. In the current policy changes to vocational services for disabled people, those making the changes do not involve disabled people in the decision making.

That disability research, particularly disability research in which disabled people are partners, does not occur frequently, likewise indicates invisibility. Research can be qualitative, quantitative, or both, but the indicators of invisibility yielded by

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[18] Lead character in a cartoon series that used to feature in some disability magazines such as the national newsletter for NZ CCS.

such research become available in a disjointed way. If, for example, quantitative research is undertaken, it is largely small-scale, and one small-scale project may operate on a definition of disability[19] which differs from definition of disability used by another project. This means that two research projects may well not be comparable.

Large-scale research is rare. A census question and post-census survey on disability was included in the 1996 New Zealand census, for the first time this century. While it has made wide scale statistical data available, it does not yet offer any means of adducing trends since it is 'stand alone'. has, at this point, nothing with which it may be compared other point of comparison yet. Finally, whether the information collected is qualitative or quantitative it is often given little attention by the shapers of laws and policies. Detailed debate on why such lack of attention occurs is outside the scope of this thesis, but the consequences, in terms of invisibility, are relevant, and demonstrable.

One of the most evident indicators is in employment. Statistics NZ (1998a) reports that 40% of disabled people, compared with 70% of non disabled people are in the labour force[20]. Employment of disabled people at 37% compared with 66% for non-disabled people. Where disabled people are in employment in the public service they are paid, on average, less than non disabled people. A majority of disabled adults under 65 years (52-55%) have an annual income under $15,001, compared to 36-45% of non disabled adults in the same age group[21] (Statistics NZ: 1998a). It is further noted that for all of the above employment data, disabled women are worse off than disabled men.

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[19] The World Health Organisation's threefold division into impairment, disability and handicap is regularly used. However Oliver (1990) summarises many objections to the definition, saying that WHO definitions do not define disability because they "attempt to make concrete that which is not and can never be...they present disability as a static state and violate its situational and experiential components" (1990: 5).

[20] Table 4.12

[21] Table 4.14

In many other spheres, actual statistical indicators are not available. But non-research information, for instance on reproductive or relationship matters (French, 1996, Morris, 1992a, Finger, 1991), is consistently reported, and by no means contradicts relevant quantitative data. Mason's (1992) experience as a disabled woman that "Our sexuality was barely acknowledged by the staff" (1992:114) is representative of this kind of anecdotal information.

Life unworthy of life? Eugenics, Euthanasia and Genetics.

Among the issues with which disabled people are confronted, few are as fundamental as the right to exist. During the years of the Third Reich, the Nazi regime killed between 200,000 and 300,000 disabled people by starvation, lethal injection or gassing (Morris, 1991, Wolfensberger, 1981).

At the time they occurred, the Nazi practices were consistent with a lot of eugenic thought throughout most of the world. They were one manifestation of eugenics in practice. Eugenics, commonly known as Social Darwinism was founded by Galton in the 1880s. It was a school of thought arising subsequent to Darwin's theory of evolution. The argument it advanced was that the purity and vitality of the human race was being undermined. A variety of disabling and undesirable (degenerate) states had arisen as a consequence of union between people who had 'inferior' genes, and this was increasing. To prevent further degeneration of the race, therefore, those with 'superior' genes, or good stock[22] were to be encouraged to increase their numbers, while 'degenerate' stock[23] were to be prevented from further breeding.

Support for eugenics was high internationally and German policies and practices drew public support. States with eugenic enactments included Denmark, Turkey,

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[22] Kevles (1985) notes that eugenics proponent, Charles Davenport, saw good stock as white, middle class, Protestant and preferably intellectual.

[23] Degenerate stock had "anatomical defects, neuropathic taints, sociopathic behaviours, and were sexually deviant" (Kevles, 1985: 46-7)

Cuba and Iceland (Proctor, 1988). Support came from diverse quarters, including socialists and feminists. Goldman asserted that those who would deny access in birth control methods would: "encourage the increase of paupers, syphilitics, epileptics, dipsomaniacs cripples, criminals and degenerates" (1917: 459).

The Nazi moves to eliminate people who did not fit the normative description of good stock ultimately brought a reaction against eugenics. Less drastic but still draconian practices associated with eugenics survived in various quarters, however. In America and Canada, institutionalisation, often combined with compulsory sterilisation was a regularly used method for dealing with people with intellectual disabilities. In Alberta, Canada, such practices were common until the 60s, and eugenics legislation was not repealed until 1972 (Buchanan, 1997).

Although there was a reaction against the eugenics movement after World War Two, the thought which had underpinned eugenics was still supported in many people's minds: a belief in the breeding of a 'better' human race, particularly by the 'weeding out' of lives seen to be imperfect. This belief has been particularly significant to disabled people, with the impact being evident at both ends of life. Newall (1996) describes such impact where the stereotypes "dominate the negative conceptions of disability are the knowledge utilised by many of us, including medical practitioners, to decide upon the quality of life of a person, and whether they should actually live" (1996: 32). Through using such a rationale, the killing of disabled people can thus be justified as 'merciful' or 'kind': a release from a life filled or which will be filled with the pain and futility, that disability is seen to embody. In this ongoing sense of unwelcome, disabled people are confronted with a discourse that seems to present disabled lives as "a burden to us, barely worth living" (Morris, 1991: 19). Such beliefs are articulated in the context of a reconfigured and reenergised eugenics movement.

Newall (1996) comments that " proponents of euthanasia seem to presume that death is a more desirable state than living with an illness or disability" (1996: 30). An example of this is prominent American euthanasia proponent Jack Kevorkian who says "The voluntary self-elimination of individuals and mortally diseased or crippled lives can only enhance the preservation of public health and welfare" (Owen, 1997: 11). There is vigorous support for such perspectives in public demonstrations legal actions, media and internet debate by euthanasia groups.

A further argument used to 'value' disabled lives is that of economic rationalism. Johnson (1997) records that the American Hemlock Society says that the population will continue to age and get sicker, so that "medical care MUST be rationed...where do you suggest rationing start, if not with those who are already terminally ill?" (1997: 22). It makes it clear that disabled people and older people are included in their 'terminally ill' group. Disabled and old people are better off dead because they use up too much money.

Attitudes towards reproduction, and the possibility of a disabled foetus are similarly stark. In many countries, regardless of how restrictive or liberal are their laws on abortion, the presence of disability is usually considered proper grounds for abortion. In the 1978 Contraception, Sterilisation and Abortion Act in this country, severe abnormality is one of three grounds upon which abortions may be obtained. The painful feelings that abortion on the grounds of disability brings for disabled women is encapsulated by Mason (1982): "You are speaking about my life. You wish me to discuss whether or not, as a woman with 'severe' disability, I think I should have been murdered" (cited in Morris, 1991: 69).

Genetic engineering has been described by Fitzgerald (1996) as the face of 'new' eugenics. In the technological advances of genetics, Fitzgerald sees the face of

the 'new' eugenics. Her concern is that genetic engineering[24], and genetic mapping[25] can be used in ways that are harmful to disabled people. She points to the uses of genetic information as feeding into decisions on selective abortions, medical resource allocations and insurance discrimination, and argues forcefully that "the concept of the geneticised self endangers the basic human rights of persons with 'bad' genes, since they are then defined out of humanity" (1996: 4).

The Human Genome Diversity Project generates ostensibly value-free information[26] which can then be used to make 'choices' about a foetus that appears to be disabled. But the 'choice' is set within the same kinds of negative thoughts, images and stereotypes that seem to have been present throughout history. Given the negative stereotypes that predominate, 'choice' is unlikely to assign a positive, or even neutral value to disability.

Like eugenics, the associated issue of genetics and what it is used for does not appear to positively value disability as one of the diverse states of humanity. Rather, disability is seen to constitute an unwanted state, a life not worth living. In the face of such circumstances, to maintain an identity in which disability is owned and valued is difficult. Disabled people may show agreement with the dominant discourse; it may be what they have heard for most of their lives. But others have begun to articulate an alternative discourse. In that alternative, human rights are one of the prominent aspects, and it is to human rights that I now turn, as the last major issue in this section.

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[24] Genetic engineering is the cluster of manipulations of reproduction or hereditary processes. It includes gene therapy where new genes are inserted into existing cells with supposedly faulty genes, genetic manipulations where it is attempted to modify or repair supposedly-faulty genes in a foetus, and cloning, where a cell from an individual or animal with 'desirable' traits is substituted for the material in the nucleus of a recently fertilised egg.

[25] Genetic mapping refers to the attempt by the Human Genome Project to uncover the entire sequence of genes in the human genome. Its corollary is the Human Genome Diversity Project which aims to map, and obtain samples of the entire range of human genetic material.

[26] The Human Genome Diversity project has been strongly rejected by most of the world's indigenous people in at least 12 international declarations. Disabled people, through organisations such as Disabled Persons International (DPI) have also expressed concern over the project's implications

Do Disabled People Have a Right? To What?

The literature on eugenics, euthanasia, abortion and genetics shows a consistent image of disability, which is itself an echo of the literature presented in the previous chapter, linking thoughts and practice throughout history, (see Stone, 1984, Oliver, 1990). Given the predominantly negative images and actions, it is reasonable for disabled people to enquire 'do we have a right to life at all'? There are no unambiguous answers to this, although various ringing proclamations appear to say that this is so. Kant[27] asserts that all persons have unconditional worth, and the American Declaration of Independence holds that all are equal. But actions tend to show that 'all' or 'equal' most often excludes disabled people.

The term citizenship, or the relationship between individuals and their societies is a useful starting point for inquiring what rights disabled people have. Marshall's (1952) text describes citizenship as comprising political, social and civil rights. The concept of citizenship was widely used by philosophers and social theorists late last century to describe political inclusion of various groups of people into society. Marshall revived the concept this century, and I have used his division of citizenship into political, social and civil rights to examine rights for disabled people.

Political rights are rights to vote, but Oliver (1996) argues that "many disabled people are denied the opportunity to exercise their political choice" (1996: 46). Information is not readily available in a range of formats, such as disc, large print or tape. Election meetings are regularly held in inaccessible premises, minus ramps, hearing loops or sign language interpreters. Technology is not so advanced and inexpensive that most disabled people can obtain their information through the internet. Televised information is rarely captioned, and voting procedures are not put into comprehensible language so that it can be understood

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[27] Cited in Beauchamp, T. and Childress, J. (1989: 71)

by deaf people[28], or people with intellectual disabilities. The lack of access to information or to facilities disadvantages many disabled people.

Marshall defines social rights as

> The whole range from the right to a modicum of social welfare to the right to share to the full in the social heritage and to live the life of a civilised being, according to the standard prevailing in the society. (1952: 11)

Social rights imply an adequate level of income. But an average of 60% of disabled people have an annual income under $15,001, or $288 a week (Statistics NZ, 1998a:14)[29]. The average weekly wage in 1996 was $571, or $29,672 pa (Statistics NZ 1997b). This indicates that for a majority of disabled people the poverty of a very low income is a common experience. The (1988) Royal Commission on Social Policy was clear that sufficient income is required to belong to and participate in a community. The experience of poverty for a large proportion of this country's disabled population indicates that social rights are unlikely to be present for many disabled people.

A further aspect where disabled people lack social rights, in the sense used by Marshall (1952), is where disabled people live in group homes, institutions or hospitals. For them life is not the ordinary life of most private-dwelling residents. They exercise few choices, and often eat, go to bed, bathe or go to the toilet according to someone else's routines. They may not be allowed to choose roommates, food, or sexual partners. Their bank accounts may be controlled by others. Social rights are indeed distant in such circumstances.

To Marshall (1952), civil rights includes more than legal rights alone: they also comprise rights of property, contract, free speech and thought, religious practice and association (in Oliver, 1996). Many of these components of civil rights are not

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[28] Many deaf people have sign language as their first language. It is not as abstract as is English. Use of clear and comprehensible language means better communication.

[29] Of these, 49% are male and 70% are female. The annual income of $15,001 is equivalent to $288 a week

present for disabled people. The New Zealand Human Rights Act 1993 does not override existing legislation that may discriminate against disabled people. For one example of the lack of legal rights, it is possible to pay disabled people less than the legal minimum wage, through an exemption obtained via the 1960 Disabled Persons Employment Promotion (DPEP) Act. Property and contract rights are often on less favourable terms. So while outright refusal, say to grant a mortgage, or health insurance cover, or to allow membership of an association to disabled people is rare, the conditions of availability may well be so limited, or financially weighted that, effectively, such goods or services are not available.

Further, free speech is often difficult to exercise. For example, considerable numbers of disabled people rely on a government-purchased service to meet their support requirements. They would find it difficult or dangerous to express complaints, or disagreement with the service because they fear the withdrawal of the service, be the fear realistic or not.

Setting the rights which Marshall describes alongside the experience of disabled people highlights gaps in political, civil and social rights. Oliver (1996) asserts that "disabled people are not citizens, at least not in Marshall's definition of the term"(1996: 46). I argue this assessment fits with the situation in Aotearoa/New Zealand.

Given the above examples of a lack of rights experienced by many disabled people, it is unsurprising that many disabled people wish to obtain legal protection and status. Since 1993, the Human Rights Act has provided legislative protection for disability. Its general approach is to specify the groups to whom the legislation applies, and prescribes legal sanctions for acts of discrimination on the basis of group membership.

However, the legal 'protection' and recognition it extends is somewhat circumscribed. Rights are based around whether 'reasonable provision' has been made, and there are many allowable exceptions. Astor's (1990) review of Australian anti-discrimination legislation that uses a similar approach points out 'reasonable accommodation' is one of several major areas needing substantial improvement. Further, as Beadle (1995) details, the way the Act is written can effectively divorce a disabled individual from the protection it seems to offer[30].

The Human Rights Commission has said that "to deny people their human rights is to set the stage for political and social unrest" (Hunt, 1996: 25). But the experience of disabled people with the use of human rights legislation in this country, has been that the very law designed to protect their rights can have the effect of denying the exercise of those rights. Human rights legislation is still open to critique and the inability of people with disabilities to have what they regard as adequate access to them, in law would seem likely to inspire the unrest that the Act was designed to obviate.

There is a last aspect of human rights legislation: rights where people are part of more than one oppressed group. Morris (1991) argues that disabled women, black disabled people or disabled gay men or lesbians "should not be treated as an 'added on' optional extra to more general analysis of disability" (1991: 12). But the 1993 Human Rights Act gives recognition to discrimination only when it arises from membership of a single group. A disabled woman may pursue remedies either on the grounds of disability or on the grounds of gender. If the discrimination has elements of both[31], the effect may be that the actual discriminatory act(s) is/are not addressed, because there is more concern to ensure correct

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[30] In 1998, the original complainant in the complaint against Wellington's bus company had no say in a settlement negotiated between Stagecoach and the Human Rights Commission, about the complaint because of the wording of the legislation.

[31] For example harassment or abuse of a disabled woman may have arise out of both factors.

categorisation than actual remedy. In short, the structure of the legislation may result in disadvantageous consequences for disabled women.

2. GENDER

Around twenty years ago, a 'second wave' of feminism gathered strength, and developed a substantial body of theoretical literature about the experience of being female, and concrete consequences in patriarchy and oppression. This feminism had a powerful effect. Morris (1991) describes the experience where:

> The deep sense of unease which I had felt since puberty was suddenly articulated by the realisation that my awareness of being excluded, my sense of a rigid, powerful set of ideas imposing itself on me was not an isolated, individual experience, but was rooted in what it means to be a woman in male-dominated society. (1991: 4)

Feminists struggled against the diminution of women's worth as reflected in employment practices, and unpaid work, sought to regain control of their own bodies and reproduction, and addressed violence, sexual abuse, education, and caring. The struggle included both activist and theoretical contributions. Marilyn Waring, Mary Daly and Rigoberta Menchú are among the women who have undertaken political activism, writing and academic activity in this 'multi-media' approach to feminism. Others of the 'second wave' were more related to one area such as performance or visual arts[32], or in writing feminist theory[33].

Many incarnations of feminist theory have arisen and supporters of these perspectives have argued their respective cases with vigour. I do not proposed to analyse these debates here. Rather this section will consider some of the feminist issues which are of both generic concern and particular relevance to disability,

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[32] For example, singer-songwriter Judy Small, or photographer Gloria Steinhem

[33] A large range of women have theorised feminism at a variety of levels. The range is wide, and includes , Shulamith Firestone, Betty Freidman, Mary Dalley, Bell Hooks and Hélene Cixous.

age and work. The issues discussed are images and diversity, reproduction and genetics, feminist research and caring.

Images: The Female Body, And Diversity

An obsession with the female body beautiful-what Wolf (1990) calls "the beauty myth"- is powerful and enduring. It has been a factor for centuries, with the 'ideal' female form externally imposed, then the ideal has been internalised and policed by women. Further, women are still exhorted, cajoled and coerced to conform to an imposed ideal of female beauty, desirability, femininity. Bartky (1986) uses Foucault's concept of power to show that ways of dressing, styling hair, having the appropriate bodily dimensions in the appropriate places, and talking, all constitute a technology of power which produces a specific form of embodiment-femininity. [34]

Wolf (1990) also argues that this 'beauty myth' constitutes the way in which female identity is prescribed, and autonomy controlled: "The beauty myth is always prescribing appearance and not appearance" (1990: 14). Wolf details many examples of how the beauty myth becomes real: liposuction and other forms of compulsive body-surgery, anorexia, bulimia and endless dieting, dressing and acting in rigidly prescribed ways, and seeking to appear forever young and available She goes on to argue that the 'beauty myth' is "seeking right now to undo psychologically and covertly all the good things that feminism did for women materially and overtly" (1990: 11). By this she means the actions stemming from the second wave of feminism, where anti-discrimination legislation was to give strength to the struggle against gender-based job discrimination and sexual harassment, exclusionary religious practices (and dogma) diminished in extent and effect, and women exercised greater reproductive control.

Although Wolf's argument is clear, consistent and well supported, the attribution of a single cause for a complex situation is ultimately unsatisfying. This is especially

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[34] Cited in Sawicki. (1992: 64)

so because the power relations in the everyday settings that she repeatedly describes conform more closely to the concept of power described by Foucault, and post-structuralists. That is, power exists in multiple and concurrent forms.

In the arena of reproduction and reproductive technologies, power, control and gender are aspects where stresses are particularly evident. From early in the century, various women, such as Marie Stopes, and organisations for the advancement or protection of women struggled for the availability of contraceptive information, so that women could control their fertility. Brookes (1986) points to the dangers to women's life that were present through repeated pregnancies, death or disease attendant on childbirth, or through illegal, backstreet abortions: dangers which signified their lack of reproductive choices. In the struggle to assert autonomy over their own bodies, some feminists such as Emma Goldman and Eleanor Rathbone looked to the eugenics movement for support.

Later, when some access to contraceptive information and technology had been gained, the struggle for control by second wave feminists was in the arena of abortion. This is still a contested arena. Although legislation change has meant easier access to abortions in many countries such as Japan, or Britain, there are still many pressures on whether or not it is available. For example, there are considerable social and spiritual sanctions in many Third World countries. However, the debate has moved all parties into, perhaps unexpected territory, through technological advances in reproductive technology.

Initially, feminists such as Firestone (1972) felt the new technologies would free women from the "tyranny of reproduction by every means possible" (1972: 193). But as test tube babies, artificial insemination, surrogacy, cloning, prenatal screening, genetic engineering and designer babies became phrases translated into everyday reality, more and more women questioned the issues the 'advances' and the implications (for example, Rowland, 1992). They were concerned that the

right to control their own reproductive capacity was being taken away by male scientists and male doctors (Arditti, Duelli Klein, and Minden 1984).

Such a belief caused many women to feel angry. Arditti et al. (ibid) articulate the sentiments thus:

> It is...women who are exploited as surrogate mothers, women who are the disappointed test tube candidates, the unhappy biological mothers....At the mercy of 'benevolent' male experts. At the mercy of technologies developed by men who see women as something 'other'....Technologies that were not made by us. We doubt that they are in women's interests (ibid: 2).

Rowland (1992) reiterates this concern in more trenchant words: "Men have always been concerned with controlling women's fertility."(1992: 8).

In discussing the implications of the new technologies for women with disabilities, Morris (1991) highlights their concerns about control that are also on a large scale, particularly how reproduction is an arena in which decisions about quality of life can be made from a limited 'scientific' basis. For example, Bailey (1996) is concerned about the way in which prenatal testing is used in relation to disability, with tests performed because it is technically possible to do so, rather than because women have asked for them. Similarly Hubbard (1992) and Rowland (1992) have both expressed concern for the 'price' women pay in anxiety. Further, Fitzgerald (1996) and Rowland (1992) say that commodification of reproduction is present for all women; disabled and non-disabled alike.

Such a common interest in reproductive technology is one area in which disabled and non disabled women can be seen to speak with common interests. Such commonality in interests does not always happen, but the image of women-indeed that of 'feminist'- has not easily accommodated this diversity of interests. Poststructural critique of orthodox ideas of rationality, and of the unified subject, has been very consistent with feminist critique of rationality which says rationality

is essentially a masculine concept, which has excluding diversity by ignoring women's understandings. However, a struggle to have women's understandings acknowledged and respected as part of diversity has not necessarily lead to acknowledgment of diversity among women. For example, McNay (1992) characterises the crossover between feminism and poststructuralism as "vibrant and productive" (1992: 2). However, she continues, there is limited understanding that the term 'woman' does not mean a unified, single perspective. The consequence of this low degree of understanding is that diversity among women receives little acknowledgment.

Similarly, Spelman (1990) argues that feminism has almost always described a white middle class norm, to which other women's different experiences are added for particular aspects, such as research. So in the same way that general accounts do not include women, so most feminist accounts speak from a limited range about women. There are "startling parallels between what feminists find disappointing and insulting about western philosophical thought, and what many women have found troubling in much of western feminism" (1990: 6). While Spelman points to some of the groups of women who have been left out of feminist analyses, such as women of colour, working class women, lesbians and Jewish women, she does not, however, mention older women and disabled women.

The challenge, as articulated by Morris (1991, 1996), is therefore to integrate all different aspects of women's identities into a feminist thought, rather than to add on the aspects to existing feminist theory. She points out how many disabled women are committed to principles of feminism, but challenges conventional feminist analyses which show neither recognition of, nor respect for diversity, as seen in disability or age:

> Although we feel betrayed and excluded by feminist analysis and activism, many disabled women still feel key aspects of feminism have great relevance to how we experience oppression and discrimination. (1996: 5)

The issues around feminist research and caring illustrate the consequences of such exclusions of thought.

Feminist Research, Diversity And Caring

Social research which does not take account of gender has been challenged for over 20 years now. Harding (1987) has provided a clearly articulated understanding that appropriate inquiry should:

> Provide for women explanations of social phenomena that they want and need rather than providing for welfare departments, manufacturers, advertisers, psychiatrists, the medical establishment or the judicial system answers to questions that they have...Traditional social research has been for *men.* (1987: 8)

Although Harding (1987) identifies the deficits of conventional research in its relation to women, she rejects the idea of a distinctive entity called feminist research methods. Others such as Reinharz (1992), and Oakley (1981) are more certain that a distinctive entity called feminist research methods exist. But Harding (1987) believes the use of more traditional research methods from a base of feminist methodologies and epistemologies is an approach that is more useful to women's interests.

It is, however, in her support of two, seemingly opposed, aspects that a key concern for feminist methodology is seen. The concern is how to express diversity among women. Harding is suspicious of the relativism that post modern thought implies and describes relativism as "fundamentally a sexist response that attempts to preserve the legitimacy of androcentric claims in the face of contrary evidence" (1987: 10). But at the same time she is conscious that there is no single explanation for women's experience, and "we should talk about our 'feminisms' only in the plural, since there is no one set of feminist principles or understandings"(ibid: 7).

The two positions do not sit together easily. Multiple explanations of reality that postmodernism has engendered, seem to lead to a morass of relativism (McNay, 1992). Postmodern critique of the rational subject, who is central to conventional 'grand theory', denies the existence of a fixed core or essence that is 'right'. By this, it denies that there are any 'givens' about people. However, much feminist theory rests on basic value judgements about women's oppression. To assert there are no givens seems, effectively, to deny women's oppression, and a number of feminist theorists are very critical of anything which appears to attack the basis of feminism. For example, Hartsock (1995) asserts that postmodern deconstruction of categories like subjectivity, with a resultant tailing off into relativism denies women any chance of articulating or analysing their oppression. Schor (1987) is even more suspicious, asking "what is to say that the discourse of pure difference is not the last or (less triumphantly) the latest ruse of phallocentrism?" (1987: 109).

The issue then is how feminist research, built from a basis of difference, can come to terms with the diverse aspects of women, who are not the unified 'other', and who have a variety of issues of their own. In supporting the need for feminist research to be more inclusive, McNay (1992) points out that "feminists cannot afford to relinquish either a general (feminist) theoretical perspective, or an appeal to metanarratives of justice" (1992: 7).

Black women have struggled for feminist research that does not exclude them through a foundation in white, middle class women's experiences, theories and values. They point out that black women have different, and equally accurate experiences of being female. Brewer (1993) emphasises that it is not just a matter of including black experience within the ambit of woman, as "gender as a category of analysis cannot be understood decontextualised from race and class" (1993: 17). Her words emphasise that recognising diversity needs to be comprehensive.

To add a few additional categories to 'women' is insufficient, since identifying with more than one group results in complexities of 'women' that are beyond neat categorisations.

Disabled women remain to be convinced that feminist research recognises their diversity. Morris (1992b) is forthright that she "has often been angered by the way that feminist research and theory has excluded disabled women" (1992b: 22). One issue which illustrates how feminist research has failed to recognise women's diversity, with unhappy consequences, is in the issue of caring, particularly community care.

Feminist research on caring arose out of the identification of the family, and women's position within it, as a key concern, and a site of oppression. McIntosh (1979) identified the family household system of a capitalist state as one where:

> A number of people are expected to be dependent on the wages....primarily
> of the husband and father who is a 'breadwinner', and in which they are all
> dependent for cleaning, food preparation and so forth on unpaid work,
> chiefly done by the wife and mother. (1979: 155)

She also made clear that caring was not recognised as productive labour. Thus, she concluded, economic dependence from unpaid, unrecognised work in caring that perpetuated female oppression. This was consistent with analyses by Wilson (1977) and Land (1989) which emphasised how the state, through social security, encouraged unpaid female labour by encouraging caring within the home. In Aotearoa/New Zealand, also with a well developed system of social security, Briar (1992a) affirmed that a similar situation existed.

The response to this was to try to free women from the burden of unpaid caring activities, and a focus on child care in the 1960s was succeeded by attention to the care of 'dependent others', notably disabled people, in the 1970s and 80s.

Feminists such as Finch (1984), Ungerson, (1987), and Dalley (1988) developed an analysis of caring, particularly community caring. The analysis is encapsulated by Finch (1984) who began "we reject so-called community care policies which depend on the substantial and consistent input of women's unpaid labour in the home" (1984: 7). She then asked "can we envisage *any* version of community care which is non-sexist?" (ibid), and decided that residential (that is, institutional) care was the necessary solution.

The 'solution' was strongly supported by Dalley (1988) who promoted 'alternative' forms of non-family care. For disabled and elderly people this was residential care, which would, she anticipated, become a "lively, integrated community of individuals....where carers and cared-for collaborate" (1988: 121). She further argued that new forms of residential 'collective' care would provide best for the interests of women who care, and the people for whom they care.

A crucial point which feminist analyses failed to understand is the nature of care. Feminist understandings were predicated on care as something that women 'do' to other groups: elderly or disabled people, (both of whom are apparently genderless). Thus Ungerson's (1987) research on caring identified only with the interests of those who provided care. She was explicitly committed to "women-centred' issues around community care, but did not seem to recognise that a woman might both receive and give care.

As Morris (1992b) points out, in a feminist analysis, there is no recognition that "not only are most carers women...but so are most of those who receive 'care' " (1992b: 30). Further, research by Jack, Dourado, Dowland and Hyslop (1982) shows the extent to which disabled women in a partnership carry out the bulk of

caring activities [35]. Disabled women can, and do regularly raise and care for their children (Keith and Morris, 1996). The post-census survey on disability (1997a) shows disabled and non-disabled women involved in caring activities (including caring for other disabled people) at substantially similar rates[36].

Feminist analyses of caring claim to protect the interests of women in general. But the analysis does not recognise that the interests of women in relation to caring includes the interests of disabled women, who have not suddenly become a genderless group of others to whom caring is 'done'. The consequences of this position are, in effect, advantaging one group of women at the expense of another group of women, and have created considerable tension between disabled and non-disabled feminists (see for example, Keith and Morris, 1996).

There are two further significant issues that emerge from the issue of caring. First, an adequate and inclusive understanding of caring remains to be formed. While women, both disabled and non-disabled remain involved in the activity, the need for this remains. The second, already referred to, is the need for feminism to develop adequate ways of addressing diversity. While there has been concern that the consequences of post-modernism will dilute all certainties to a timorous relativism, the consequences of a blinkered and non-inclusive concept of women are equally disastrous. McNay (1992) expresses cautious support for a rapprochement, between the straining of feminism and looks to a syncretism from which feminist essentialism (it's all and only gender) and postmodern relativism (there are infinite differences) make better recognition of diversity and structural inequality possible.

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[35] In Jack's survey, over 80% of the women with disabilities took responsibility for household tasks that are commonly regarded as components of care. Women both under and over 65 shopped, cooked, did the laundry and the housework.

[36] Tables 67 and 68

Among feminists who believe feminist postmodernism is possible, Sawicki (1992) provides a conceptual framework for addressing diversity among women. She argues for the concept of multiple identities, and points out that diversity is likely to increase the places from which resistance to dominant discourses takes place. In the third section, I return to Sawicki's argument, and explore its use in an approach to identity for disabled women.

3. AGE

Old age is accorded scant regard in Western society. It is synonymous with many negative images also familiar to disabled people: decay, dependence, inability, senility, obsolescence, passivity, burdensome responsibility. It is assumed that chronological years correspond to ageing which, in turn, represents all that is slowed down and incapable. Among the more prominent issues, is the nexus of family relationships, caring and costs of support. This section considers the ways age is seen, from bio-medical, disengagement and delaying the decline of age perspectives. Issues of dependency and caring are addressed. The section begins with an overview the images of ageing, as a counterpoint to a life-span approach.

Images

Hareven (1982) says it is a Western trend in the last century to see ageing as a distinct, negatively featured period in life, rather than as a natural process within a life span. She believes that instead age should rather be seen within a life course approach where:

> Rather than viewing any stage of life such as childhood, youth or old age, or any age group in isolation, it is concerned with an understanding of that state in an entire life continuum. (1982: xiii).

This implies a recognition of life as a process, rather than a series of events in which people jolt suddenly from one stage to the next, and become different people in that instant. Macfarlane (1994) expresses a similar perspective about

ageing and disability. She is amazed at "the notion that what a disabled woman required or needed or, indeed, wanted at fifty nine will be different on reaching the age of sixty". (1994: 256). She further comments that needs do not suddenly change over a day to something else.

While they do not oppose the concept of life span or life course, Thompson, Itzin and Abendstern (1991) point out that negative or hostile Western attitudes and practices related to old age have not just begun to occur recently. They point to long standing and widespread stereotypes about age. Probably the best known encapsulation of this is Shakespeare's summation[37] of the seven ages of man where old age is "second childishness and ripe oblivion...sans teeth, sans eyes, sans taste, sans everything".

Thompson et al. (1991) show how stereotypes of 'old' were reflected in laws and customs of inheritance that gave little protection to older people in Europe. There were commonly written contracts to protect the access of older people to maintenance. Tensions abounded where two generations co-resided, and in consequence, there were even lawsuits against close relatives taken by aggrieved older people[38].

Such negative stereotypes about age, that have long been in existence, are mostly held by people who are not old. Thompson et al. (ibid) highlight how the images are very much removed from the way older people themselves view being old, and offer some possible reasons for this. They say:

> We seize on myths because they help to make sense of life, to justify the cruelties of life....But we seize on the myths at a price. The myths of ageing which we are fed in youth and middle age simply do not fit the typical

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[37] In Act II, scene vii of *As You Like It*. Spoken by a gentleman attending on the banished Duke.

[38] Thompson et al (1991) give examples such as English case law of the late 15th century which involved the provision of food, drink and housing, and 17th century Swedish Court records, which deal with cases of food provision, cursing and physical violence (1991: 25-28)

experiences of older men and women. To them, those stereotypes are degrading images...which they unhesitatingly, -sometimes indignantly, or with acknowledged apprehension -reject for themselves now. 'I don't feel old' is a cry of protest against a myth that causes both pain and fear: a call for the recognition of human individuality and resourcefulness at any age. (1991: 250)

A lifespan approach is different from the well established images and discourses on age. Opie (1995) points to a variety of discourses about age which exist concurrently, and at a variety of different levels. They include discourses on organisational policies and practices of work, the work of social workers with their old clients, and, importantly, the theories which inform practices (1995: 2-3). I turn to the last of these discourses, where Opie (1995) discusses three of the most widely used approaches to ageing to perceive influences on the theoretical discourse. The approaches are bio medical approaches, disengagement theory, and an approach to age as decline.

Approaches to Ageing

The bio-medicalisation of gerontology, or the systematic study of ageing may be seen to underpin or fit with other approaches to ageing. But it also has a distinct life of its own (Estes and Binney, 1991). Bio-medicalisation takes effect principally through geriatric medicine. In this framework, age itself gives rise to a medical condition, and thus is the locus of attention. So age alone is seen to be sufficient reason for an infirmity or illness, so that when an older individual develops symptoms such as incontinence or confusion, it is explained in relation to their age. Thus the approach is similar to that of medical models of disability, where the problem is similarly located within the individual, with the cause being some inherent defect (Oliver, 1990).

Individualisation, and focus on age as a state apart has also been evident in sociological discourses on ageing. One approach in particular, disengagement theory, has been very influential. In this approach, people are seen to age into a progressively diminished space, while life inevitably retreats from them. Havighurst, Neugarten and Sheldon (1968) describe a process where "people grow older, their behaviour changes, the activities that characterise them in middle age become curtailed, and the amount of social interaction decreases"(1968: 61). But Oliver (1996) disagrees with disengagement theory because he says it does not provide an adequate analysis. He points out that , in relation to ageing with a disability, no account is taken of external factors such as pension levels, or social attitudes, neither does it consider how individual differences or conditions can substantially alter the decay which the approach regards as inevitable.

On a more global level of critique, Oliver (1990) points to the dominance of "personal tragedy theories of disability and ageing" (1990: 1) which imply expectations of an able-bodied "normality" that are contrary to the process of ageing. Adaptation to this expectation may be in the form of accepting that one has a diminished existence, and withdrawal from everyday activities is to be expected.

Other critique of disengagement theory comes from Turner (1995), whose complex critique begins by arguing that there is no sociology of ageing because there is not an adequate sociology of the body. He goes on to say that the body of an older person is the site on which a lifetime of experiences is inscribed in physical form, it is embodiment. This inscription process includes internal understandings of one's life. But he points out that how old one feels oneself to be do not necessarily translate directly to a body's actual years. The consequence of these factors, he summarises, means there is a contradiction between the external bodily processes of ageing and the internal sense of youthfulness.

Because disengagement theory does not address these contradictions, Turner feels that the theory does not adequately explain ageing. He argues that disengagement theory looks only to ageing as a social construction, and does not have the capacity to explain how biological, social and cultural features of a whole life may be integrated.

A third stance, consistent with the first two, sees ageing as a time in which all purposive activity should be directed towards delaying decline (Wilson, 1991, Fry, 1992). In this stance, ageing is seen as a time in which any purposive activity should be directed towards delaying decline. Diet, therapies, fitness regimes, cosmetic surgery or techniques that are seen to induce longer, younger lives are tools for this purpose. Featherstone and Hepworth (1991) comment that such techniques, which are often very sophisticated, are a way that older people with the necessary money can stave off an unwanted state of ageing. An implicit assumption in this stance is that ageing should be avoided because it is an inherently undesirable state, and to be young(er) is to be 'real', so every effort should be made to drink at the fountain of youth. In this approach the state of age is, in effect denied.

The two last discourses are particularly significant, Opie (1995) asserts, because they implicitly say that ageing is a non-productive state, and inevitably means a diminution of humanity. A reflection of this diminution can be seen in debates on assisted suicide, also called euthanasia, where it is often said that older people will have a diminished quality of life, or are a drain on community resources. This sequence of negative thought translated into negative discourses and negative consequences in policy and practice is a similar sequence to that which is seen in the discourse about disability.

Dependency

Before examining the extent to which disability and age are linked, dependency, caring, and the way that these two major issues relate to age will be addressed. First, with respect to dependency, Green (1993) argues that it is a central concept in gerontology. He outlines aspects of the concept, arguing that old people share a legacy of "subjection to certain conditions and procedures of recognition certain methods of knowledge production, central to which is the grammar of dependence" (1993: 95). He goes on to link dependency and care, saying that acts of care relate directly to conditions of dependency. He argues that care and dependency are, in effect, on a continuum, and not separate entities, and form part of a single discourse. While I acknowledge that the two issues are closely related in reality, I have artificially separated them here so that the particular characteristics of each are more apparent.

An increasing proportion of our population is ageing: there are more older people as mortality falls and life expectancy increases. The 'greying' will increase as the people who, forty-odd years ago, were part of a post-war baby boom, themselves become old. This creates anxieties for a number of sectors of the population who worry about caring and who will perform it, and who worry even more about the cost of and existence of dependency. The concern has increased markedly over the last 20 or so years, particularly in America (Binstock, 1985, Daniels, 1988, Fraser and Gordon, 1994). In Aotearoa/New Zealand, the concern has become pronounced over the last five years. Some government welfare agencies are urgently trying to find ways to diminish dependency, others are concerned at what current and projected health care costs.

The commonly-held stereotype of age dependency is that because age inevitably represents decay and dependency, and that the numbers of older people will increase greatly, it will cause overwhelming demand on the public purse. Such stereotypes tend to be well supported by orthodox economic thinkers, and

agencies, for example World Bank (IBRD) (1994), or the Australian Economic Planning Advisory Council (EPAC) (1988). But analyses of these reports, particularly by Encel (1994), question both the accuracy of the claims and the assumptions upon which they are based. Encel also says that to focus on only one segment of the total dependent population constitutes an inadequate base for policy directions, and ignores other important factors in the total picture.

The concept of age dependency is also addressed by Arber and Evandrou (1993), who look at the way that age is medicalised by the use of age-specific criteria for entitlements in medical settings. Examples include annual medical screenings for all over a given age, regardless of their health, and the requirement of doctors' certificates for older peoples' driving licenses. They argue that dependency is created in both social and medical contexts.

In earlier work, Russell and Sauran (1991) point out that independence is not a free-floating, value, based on services or costs. This is consistent with the findings of other research. Thompson et al. (1991) emphasise that the ways older people themselves define independence and dependency is very different from a 'costs of caring ' orientation. Russell and Sauran's later (1994) research finds that older Australians identify independence with autonomy, "I am my own boss" (1994: 89). rather than with location, or being at home.

In the concept of age dependency, financial autonomy is an important factor. Wilson (1994) highlights its importance, in a discussion on the presence of money. She points out that the old people with savings and investments which put them well above the poverty line operate in very different structures, as they are able to purchase services, and thus retain control over their lives and decision-making (1994: 46-8). She further argues that if dependence is a socially constructed concept, associated concepts of independence, autonomy and quality of life require more careful delineation.

In discussion of their research findings, Russell and Sauran (1994) point out that older people are aware of some of the contradictions in the discourse about dependency, but are not always aware of their own contradictory positions. They define independence for themselves very differently from conventional descriptions, but believe the conventional negative descriptions such as "senile" or "people sit around and wait for the end" (1994: 100) apply to other old people. Russell and Sauran (ibid) believe this may represent strategies adopted by older people in order to deal with a discourse seen to be controlling.

Care And Age

A further issue of age, closely related to dependency, and similarly a contested one is care. Care is a taken-for-granted concept, including activities of nurturing, attending to another's needs, servicing, being with. The people who use some form of care are most often older people[39]. Caring in paid or unpaid (or formal and informal) settings is predominantly performed by women. When caring is unpaid, it is often called community care. If the caring is paid, it is also performed predominantly by women and is usually poorly paid (Craig, 1992).

Feminist critiques of caring, for example Ungerson (1987), Querishi and Walker (1989), have pointed out how women's extensive involvement in providing caregiving impacts negatively on their social, emotional, financial lives and their employment. The 'solution' to the resultant situation in which women find themselves, as articulated by Finch (1984) and Dalley (1988) is to support alternatives to family-based care: communal or residential provision for older or disabled people.

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[39] From the data in the 1996 post-census survey on disability (Statistics NZ, 1998a), I have taken the numbers of people with disabilities who receive help with everyday activities as a proxy for receiving care. Care recipients over 65 use 60% of such help, while adults between 15 and 44 use 31%. (Table 4.9)

There has been vigorous opposition to this idea, notably from a disability perspective. Keith (1992), Oliver (1990) and Parker (1993) are among those who point out that the 'solution' proposed is unacceptable. Morris (1991) encapsulates the contradictions of the proposal:

> Disabled and older people experience daily the inadequacies of 'community care' and would agree with everything that feminists... say about the isolation, poverty and sheer hard work which too often characterises both their lives, and the lives of their carers. However, disabled and older people as individuals, and through their organisations have, almost without exception, put their energies into achieving a better quality of life *within* the community. (1991: 153)

Within caring, the development of a voice for informal carers in the form of organisations of carers has been significant. Groups for those who provide care, for example the Alzheimers Society, have grown in size and influence over the last 20 or so years. These groups usually have different analyses and agendas from feminists. Where many feminists advocate changes to the situation, carers characteristically look to a continued relationship with the individual for whom they care. For older people, care givers are often elderly themselves, largely female, and caring informally for a partner or close relative. What carers groups usually want is adequate provision of support for their needs, and acknowledgment of the value of their caring. In short, carer groups tend to focus on getting on with what is generally acknowledged as a stressful task (Opie, 1995) with support, and do not commonly reflect on the way in which the care they give replicates and reinforces existing relationships of power.

Pitkeathley (1989) notes that fundamental relationships between caregiver and care recipient are unchallenged by this focus, while others are more critical of the stance. For example Parker (1993) believes that carer positions are "weak because, while they acknowledge the needs of disabled [and old] people, they do

not challenge the social creation of disability and, therefore, of carers" (1993: 253).

A further consideration is in the way care itself is defined. Carer groups characteristically see care as a one-way relationship, so that carergivers are not also care recipients, or that old people receiving care may also give care to their caregivers. Yet research by Opie (1992) identified that some older people, identified as caregivers, were disabled and required care themselves. Earlier, Jack et al. (1982) found that a large proportion of older disabled women in partnerships, and with needs for caring themselves, undertook very high levels of caring activities.

In her discussion of women with intellectual disabilities and caring, Walmsley (1993) argues that "caring and dependency are not necessarily dichotomous: that in some situations it is not possible to identify one person as 'carer' and the other as 'dependent' (1993: 136). But if any possibility of balance and reciprocity in care is recognised in conventional conceptions of caring, it is seldom acknowledged. The consequences of this false division include policy which is " Blurring the common interests of the two parties, both of whom may well experience exclusion from the labour market, poverty and marginalisation" (ibid: 139).

In her research on caregiving, Opie (1992) uses the concept of appropriation of text to describe how matters spoken by research subjects can be interpreted and distorted by the 'authoritative' voice of the researcher. I have extended the concept to describe the dynamics in a carer-cared for relationship, to argue, that the (legitimate) needs of carers should not be seen to speak for older people in caring relationships. My final paragraphs therefore turn to the ways in which older people may be articulating some of their issues.

Munford (1994) points out that the bulk of literature on care-giving focuses on what the care-giver experiences, so that the issue is seen in terms of solutions to a technical problem: how to do or solve caregiving from the perspective of the caregiver. To this age-as-a-problem orientation is added images of age-as-dependence and age as diminution of competence or capacity to think

Orthodox images mean, according to Gubrium and Wallace (1990), "we do not, by and large, see older people as 'theorising' about such matters [caring]" (1990: 133). As with disabled people, a dominant discourse about age is developed by reference to what others think, feel and say. This has been called (Bogard, Wicks and Hunt, 1993) the "we know what's best for them" syndrome[40]. Yet old people are quite capable of analysing and naming their world, in what Gubrium and Wallace (1990) call "ordinary theorising" (1990: 146-7).

The issues of power and control are features in the lives of both old people and disabled people. In both instances caring and dependency serve to contribute to inaccurate images, and both live lives that are substantially shaped by others' control. When Munford (1994) points out that power relations also operate on caregivers, so that both they, and the people for whom they care are cast into inferior and devalued roles, it is a reminder of the need for analysis at several levels if power relations and dominant discourses are to be addressed.

Change to the images and lives of older people is likely to involve the many others who are designated as carers. Munford asserts: "we are constrained by the discourses we are subject to, but we can also be part of the production of discourses and contribute to their maintenance" (1994: 270). The statement implies that just as various interests have been responsible for the development of a discourse, so change to the discourse is the responsibility of more than one

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[40] Phrase used in presentation of a workshop about attitudes to disability. The workshop was developed by Bogard, Hunt and Wicks for the 1993 Yearly Meeting of the Religious Society of Friends in Wellington.

interest alone. The extent to which responsibility for change to a discourse about age will be shared is arguable, but the possibility arouses optimism.

4. WORK

In this section I use the term work in its broad sense of purposive activity that gives meaning in the day to day life of most adults. In this word I also include the activities of daily living, and vocational or pre-vocational activities undertaken by a proportion of disabled people, and the caring and household work that is characteristically undertaken in unpaid form.

I have used the term work to indicate its broad scope, but I have usually indicated more precisely what it involves, by referring to work as paid or unpaid. While employment, or paid work is a major preoccupation for adults throughout the world, it is not the only form of work. All the other ways in which work is undertaken I refer to as unpaid work. At times, the coverall-term work is used as an alternative, and context makes it clear which variety of work is under discussion.

This section begins with an overview of work practices and how these practices advantage certain groups. From there I consider how work has particular impact for women and for disabled people.

Patterns of Work

The nature of work, who undertakes it, and how it is performed has altered considerably over time. In Europe, as rural-based economies became industrial or manufacturing based, work changed from an occupation that had often involved all members of a family, and took place in or around home. Instead, it became an occupation to be performed in distinct locations such as urban factories or removed from home. Increasingly, a gender-based individualism predominated,

where men were responsible for 'supporting' the family via their paid work, while women undertook unpaid work in the home to maintain the family. Paid work became an activity for which an individual alone was responsible, rather than a project to which members of the family could contribute.

The work that is largely associated with women's labour in the home, has been little recognised as work, and accorded minimal value: it is almost always unpaid. Waring (1988) points out that it does not feature in national accounting systems for work, because it is seen in orthodox economics as non-productive. It is an error to regard this as a recent phenomenon, an effect of changes from rural to industrial economy. Bittman (1990) shows a long tradition of women doing much of the unpaid labour in the home. However Delphy (1985) Waring (1988) and Walby (1990) are among the many feminists who highlight the inequities of disvaluing and discounting unpaid work, and demonstrate how this is predominantly a gender issue.

Work in the pattern of industrialism has changed again during this century. Many companies have become global in nature, aided by technology that enables rapid and reliable communication or information sharing. It has meant that work practices are more alike internationally, as they fit to the requirements of an international market. Women have been little advantaged by such developments. Paid work that is seen to relate to caring or housework is, in the labour market, accorded low status and poor pay, while unpaid domestic labour continues to be regarded as devoid of value (Waring, 1988).

Not only has the overall context of work changed, but how paid work is performed has also changed. Employment practices in Aotearoa/New Zealand illustrate this. Permanent (that is, long term) employment, was the common expectation for most men in paid work over much of this century. Employees of government departments expected to have a career with one employer, such as the Post Office

(Henderson 1990). Others, in private employer such as a bank, department store or voluntary organisation would expect to remain with the firm.

Over the last 15 years or so, this employment practice has largely disappeared; the focus has been increasingly a contract-based approach. In a modern approach, paid work is episodic, and short-term in nature. Peaks of demand are filled by staff contracted in for the specific task. Where employment is permanent, it is, increasingly, part-time. In 1990, 205 women per thousand worked part time, while in 1998, this figure rose to 282 per thousand (Statistics NZ, 1998c).

Work: Who Benefits?

It is pertinent to consider who benefits from the current structure of work. Work has conventionally been structured so that the benefits have been, in the main, experienced by a limited group. Certain people undertake labour at a low rate and this enables others to benefit more than those who undertake the labour. The labour that women undertake in both paid and unpaid forms, but particularly unpaid, is of benefit to men (May, 1992, Joshi, 1992). A similar situation exists for other groups, including disabled people who claim their work on low pay advantages non-disabled people (Stone, 1986).

Those who gain most from work are characteristically seen to be white, non-disabled males . But advantage and disadvantage in work is not always straightforward, as disadvantage and advantage may be experienced at the same time and to varying extents. While a non-disabled white woman who is a full-time carer for children may be less advantaged than a Maori non-disabled man in full time employment, it is difficult to estimate how that compares to the disadvantage of a disabled white woman who provides unpaid care for her parents. Such situations highlight the interplay of identity and disadvantage, confuting simplistic analyses

So while the subsequent section draws substantially on material relating to women and work, it serves to highlight the issues experienced by women which are similar to those experienced by other marginalised workers. It demonstrates that issues of work experienced by women are often similar to issues which disadvantage other groups. It further constitutes a useful counterpoint to work issues for women with disabilities.

Women And Paid Work

Although the extent of women's involvement in paid work has expanded considerably over this century, it is not a new phenomenon. For centuries women have performed rural or agricultural labour, factory work, domestic service, teaching, sexual services or mining[41]. But as Roberts (1988) points out, women who worked outside of the domestic situation, such as miners were likely to be criticised, because they were seen to be outside their 'proper' sphere.

Roberts (ibid) also notes how these criticisms "arose out of contemporary [19th century] assumptions about women's work"(1988: 14). Given that paid domestic service was a widely accepted practice for women it is reasonable to believe the assumptions were not about women's work as such. The matter was more where and what kind of work women should do rather than whether they should undertake paid work at all.

A belief that women should properly work in the domestic sphere has been present for several centuries (Hall, 1979), and was particularly strong in Aotearoa/New Zealand during much of this century (May, 1992). Although occupations in which women are now able to work have increased considerably, there are still strong societal expectations that women should perform 'suitable' work and in the home. Causton (1991) describes a woman who has built up a business of doing

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[41] Both above and below ground

housework for others from her own home with approval. The greatest praise is for the way that paid work can be fitted around unpaid work, in the form of childcare.

That the work is either domestic or consistent with the domestic caring role which women are characteristically associated, such as nursing or teaching, does not mean that the work is adequately paid. Where 'women's work' has been paid, it has been associated with low rates of pay (see, for example, Vicinus, 1985, Roberts, 1988).

Women have joined the workforce in slowly increasing numbers over this century: and a rise in labour force participation rates has been more pronounced in the latter half of the century (Horsfield, 1990). The participation has been shaped by, not only the economic climate, but also by domestic situations or carer responsibilities. The cost of childcare, alternative care or domestic help can be large, and part-time work was seen to be a useful response to this situation. But this factor does not adequately explain why part time work is so overwhelmingly associated with women. In 1997, 282 women in a thousand worked part time out of a total of 385 per thousand part time workers (Statistics NZ, 1998c).

While part of the reason for this may lie in employers' desire to manage their labour market (Horsfield, 1990), government policy which shapes the overall economy is also likely to be a factor. During the 1980s and 90s there has been an international move towards the policies and practices of right-wing economics, reinforced by international agreements on trading practices. In this new economic orthodoxy, part-time work represents greater efficiency and greater flexibility. And since the bulk of part-time work continues to be done by women, it is on them that these changed work practices have the greatest effect.

In both part-time and full-time employment, women earn less than men, for the same or equivalent work, and this has been an extremely durable feature of

women's work. In this century, there have been repeated equal pay campaigns before the enactment of equal pay legislation, such as the Equal Pay Act, 1972. But neither campaigns nor legislation has removed the problem. In 1972 average hourly earnings for women were 69.9% of men's average hourly earnings, but by 1990, the proportion was still only 80.8% (Horsfield, 1990: 85). By 1996, the proportion was 80.6% (Statistics NZ, 1997b).

Part of the reason women earn less is that many are part-time, and thus work fewer hours. But a further and more significant factor is that they are often paid at a lower rate. In 1996, women 's hourly rate was, on average $14.02, while the average male rate was $19.26 (Statistics NZ, 1997b). This is a reflection of gender segregation whereby women are concentrated into distinct occupations; horizontal segregation, or cluster at the lower levels within an occupation; vertical segregation (Horsfield, 1990). Horizontal segregation is seen in the 1996 Census, which shows women to cluster into sales and service and clerical occupations, while the largest numbers of men worked in trades or in legal, administrative or managerial occupations (Statistics NZ, 1997a). Vertical segregation is seen in public sector data, where men comprise 90.7% of public service managers (EEO Unit, 1992).

Disabled Women And Paid Work

For women with disabilities there are generally similar features of low pay, part time work and occupational segregation, though for each aspect of paid work, women with disabilities are in a substantially worse position than either women without disabilities or disabled men. As indicated earlier, only 37% of disabled adults are in employment, compared with 66% of non-disabled adults[42]. This is even more significant over 60% of disabled adults are not part of the workforce. In contrast, a quarter of the non-disabled adult population are not in the labour force

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[42] Table 4.12

(Statistics NZ, 1998a). Of those disabled people not in the labour force, 59% are women[43] (Statistics NZ, 1997a).

When disabled women are in employment, a substantial proportion of them will be on low pay. In the public service, 71% of the women with disabilities were on or below the third-lowest step of the pay scale. Forty one per cent of men with disabilities had a similar income (Burns & Gray, 1989). Hourly earnings also reflect this. The male-female difference in earning rates already mentioned of $19.26 and $14.02 (Statistics NZ, 1997b) is replicated at lower levels for disabled wage-earners. In the same year, men with disabilities earned $14.42 while women with disabilities earned $11.16[44] (Statistics NZ, 1997a).

For disabled women the situation of occupational segregation, both horizontal and vertical is similar to that of non-disabled women. Vertical segregation is reflected in the low rates of pay. By 1992, 61% of disabled female public servants earned less than $30,000 (EEO Unit 1992). In terms of horizontal segregation, disabled women in paid work are concentrated predominantly into service and sales, clerical, elementary occupations and professionals. Non-disabled women also grouped into service and sales, clerical professionals and technicians[45] (Statistics NZ, 1997a).

Unpaid Work: Disabled And Non Disabled

Paid work is one area in which women, both disabled and non disabled, experience disadvantage. However, women are also involved in unpaid work to a substantial extent. The amount and nature of unpaid work for women with and without disabilities shows some distinctive variations, and tends to be less than consistent with assumptions about the nature of caring in which so many women are involved.

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[43] Table 70
[44] Table 71
[45] Table 64

Non-disabled women are more likely than non-disabled men to perform unpaid work, both within and outside of the household. Forty nine women in 100 compared with 42 men undertook unpaid work outside the household; 55.8% of those doing unpaid work are women. Unpaid work outside the household is most likely to be undertaken by people in part time work, and of those part timers, 76.5% were women. (Statistics NZ, 1998d). The unpaid work of women was largely in administration and policy work, household work or childcare, and teaching training and coaching. Men largely worked in similar areas. Such a pattern of occupations is similar for disabled women and men[46] (Statistics NZ, 1997a).

Unpaid work within the household is performed by the overwhelming majority of adults: 84.7% in the 1996 census. A greater proportion of this work is undertaken by women who comprise 54.2% of the people performing work in the household.(Statistics NZ, 1998d). This may appear to underestimate the extent to which women undertake household work, but it includes repairs and maintenance or gardening which have been more commonly associated with men. 59% of those who undertook childcare were women: of those who undertook caring for those who were aged, ill or were disabled, 63% were women (Statistics NZ, 1997a).

What is less expected is the extent to which disabled people engage in unpaid work in the home: while little might be expected, the rate of involvement confutes the expectation. In the 1996 post census disability survey, 82.7% of disabled people participated in such activities; 85% were disabled women. Fifty six per cent of the disabled women who undertook childcare were women, while 59% cared for those who were aged, ill or disabled[47] (ibid). The figures are highly consistent with Jack et al's (1982) research in which disabled women performed substantial

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[46] Table 68
[47] Table 67

amounts of caring work. Definitions of care in which disabled women are predicated as passive recipients are seen to be less than accurate when disabled women are undertaking caring work very little differently from non disabled women.

This overview of work patterns highlights how work, both paid and unpaid, forms and re-forms in ways that are both familiar and, at the same time, unexpected. The more expected features are those associated with women's work. The probably less known aspects are in relation to work for disabled people, particularly women with disabilities. What is less familiar is the extent to which there are linear and unsupported assumptions about caring: who does it, and to whom. The differences and complexities of this section form a useful backdrop to questions of identity, addressed in the third section.

5. INTERSECTIONS

To this point, I have described features of age, disability gender and work in separate sections. I shall finish this section by highlighting the common areas of interest as seen in the literature. I note that the linkages of the literature should not be seen to prescribe the actual linkages or the extent to which they are experienced by the disabled women who I interviewed. The lived experience of any linkages would be in far more complex and dynamic forms than academic literature could reasonably be expected to reflect. So the literature forms a backdrop of potential or likely linkages rather an accurate summary of actual events.

It is clear that images of disability age or gender match very poorly with what is experienced by these people. The images are especially poorly matched with reality for old people and disabled people, but the ongoing oppression, perpetuated by images of the 'perfect' female body is also evident. Women who

are disabled, old or both will regularly encounter these images, and their concrete results in laws, policies and practices. Images impinge on all three groups.

An allied linkage to images occurs in relation to gender and disability. There are concerns of control of fertility in both genetics and in reproductive technology. Women, disabled and non-disabled are faced with a trend to move control away from women and into the hands of male scientists and doctors. For disabled women, the issue is not only in the technology, but also in their right to bear children at all. Further, there is a tension implicit in the technology and its relationship to control: that disability is seen to be a legitimate ground for abortion is degrading to many disabled women, while most non-disabled women who are pro-choice do not see any reason to review its status.

The issue of diversity is thus of mutual concern to women and to disabled women. To recognise diversity, disabled women argue that the term 'women' and what constitutes the interests of women need to be substantively reconceived. It is not adequate, they claim, to add on special interest groups at appropriate times, while a base concept of women does not include them. The tension is seen in the issue of caring, where a feminist approach to caring, which claimed to 'free' women, proposed measures that would oppress disabled and older people. In the solution proposed, disabled women did not see any recognition of their interests.

Caring also has commonalities for older people and disabled people. In both instances, the description of the caring relationship is described in linear terms. For both, caring is something that is done to them, rather than the more interactive or flexible arrangement that is often experienced. People such as older disabled women may be designated as carers, but may also have their own needs for caring. The rigidity of the description is exacerbated by an assumption that when carers articulate their needs, this should be taken to represent the interests of the person who is cared for.

Dependency is similarly of concern to disabled and old people. Dependency has for some time been a central part of images about disability. But age has, for some time now attracted an additional concern: cost. As an increased proportion of the population ages, and simultaneously lives longer, economists and politicians have worried about the burden to the economy that older people are seen to constitute. As government increasingly contains its costs, the application of an economic argument to perceived dependency in disability seems likely to arise.

In work, particularly the forms of work which have been associated with women, disability, gender and age all have interests in common. Women's work is still substantially associated with paid and unpaid caring work, and caring is an activity that both disabled people and old people use. And though caring activities are of actual significance to all three groupings, its importance is poorly acknowledged in society, and this is reflected in a low rate of pay.

For the linkages and tensions I have noted above I have not attempted to provide answers. Few unexpected or new issues are seen. Issues of caring, dependency, image and work have been raised on a number of other occasions over the last decade. While changes that impact on people in these groups are almost certain to take place in a political or social arena, it is both feasible and necessary to address the thoughts and theoretical debates which inform the changes. The orientation to change is pursued in the next chapter, where I articulate approaches to identity and how it can be conceived through alternative approaches.

IDENTITY AND POWER

Identity is formed within relationships or interactions with other people. People find parts of their whole identity in relation to what others tell them: about how they are (for example 'my clever little girl'), and about their group ('a girl? oh that's disappointing'). Identity also comes from experiences: knowing one is likely to be discriminated against because one is seen as disabled is unlikely to be a positive experience of disability. It is hard to form an identity in which disability is valued if one hears negative images of disability, or finds that there seem to be few ways to relate it to other aspects of identity.

This section therefore explores identity and how it is constructed in relation to disabled women. It begins with a description of the orthodox understandings of identity for women with disabilities, and of limitations or problems arising from them. Because of the central part it plays in the construction of identity, power and the relations of power are discussed at some length. In the discussion, both the traditional formulation of power and alternative conceptions are canvassed. Alternative conceptualisations of identity, often suggested by disabled women themselves, are then outlined, and the limitations of these conceptualisations are also discussed.

The discussion then moves to how identity may be reconceived by using pluralist approaches. I examine how pluralist approaches are used to reconceive identity in relation to ethnicity and to women. In closing this section, I argue that the insights above can be applied to identity for disabled women. I further suggest that the use of concepts drawn from pluralism, such as "in between and "multiple identities", is a more useful approach. Not only does the use of such an approach more adequately comprehend our identity, but it also presents a further tool for interrogation of conventional identity. It more accurately reflects living as disabled

and/or female and/or old, and/or black and/or lesbian and avoids the difficulties of dualistic thought.

Identity: Conventional Views

Bhabha (1994) asks: "How do you constitute a set of identities, or range of identity which does not locate you principally in one or the other?" (1994: 197). Women with disabilities have had their identities constituted by others in the dualistic way that he questions. These ascribed identities are fashioned by assumptions that disability and female relate in an either-or fashion: either the identity is all an issue of female or all an issue of disability, and any relationship between the two is seen as unproblematic.

Disabled women who write on disability such as Morris (1991), Asch (1988), Keith (1996), Begum (1992), Vernon (1996) outline various aspects of what it is to be a disabled women, and the complex nexus of assumptions, expectations and power relations underlying identity. For instance, when Keith (1996) writes that she has been "doing disability all day long" (1996: 71), she writes principally about disability, but she also illustrates that this includes fulfilling internalised gendered expectations in the "doing" of disability. Those expectations include that she, as a woman, would not exhibit anger.

For example, when she became verbally angry with a non-disabled male who was obstructing her activities, friends became upset, feeling she had been "unnecessarily aggressive" (ibid: 82). Reflecting on this, Keith notes that in the attempts disabled people make to strike a balance between dependence and independence, disabled women are more concerned to please, help and placate, or to suppress any manifestations of anger: "[disabled] women, particularly, find it hard to know how to handle all the anger" (ibid: 83).

The assumptions which comprise a 'disabled identity' seem, on the surface, unambiguous. But contradictions and ambiguities are embedded in their ostensibly-straightforward nature. An example of this is the issue of "young carers", who are "shouldering the burden of caring for sick or disabled relatives at home" (Keith and Morris, 1996: 89). The issue illustrates contradictions between woman-as-carer and disabled-as-dependent-on-carer. Mothers who have a disability are automatically assumed to be dependent, and their children are seen to be "taking responsibility for the care of their parent" (Aldridge and Becker, 1994: 33). Keith and Morris (1996) point out that parenting, whether a woman has or does not have a disability, still involves all of the caring things that adults do to look after a child.

Fine and Asch (1988) elaborate on the contradictions of caring when they point out that if women have a stereotyped role of providing nurturance for men, such as in cooking, feeding and spouse care, the disabled stereotype of dependence and passivity is in contradiction to this. Such a contradiction arouses anxieties. They comment:

> If men can accept emotional sustenance only from women who can provide the maximum in physical caretaking, the woman with limitations may be viewed as inadequate to give the warmth, companionship and shelter men traditionally expect from their mates. (1988: 17).

Vernon (1996) shows further contradictions in a disabled identity for disabled women. She notes how her disability was a 'tragedy' because:

> I was a girl....I would not be able to marry a sighted man or a blind man, as it was thought impossible for me to be able to fulfil my womanly role of wife and mother. (1996: 49)

Her ethnic background prescribed no way for disabled women to be active, to be independent and to make choices. For example, her father "did not want me to work and have a career, because he did not see that to be a woman's role" (ibid:

49). By contrast, a male with disabilities of the same ethnicity would be able to act in an independent manner and have choices in his life. He could still be a husband and father, and have a career.

These writers highlight that in the myriad ways that identity is shown, and notably in terms of relationships, reproduction, ways of interacting, patterns of working and having control over their (our) own life there is a poor fit between women with disabilities and the 'given' disabled identity. It is a 'disabled identity', to which they appear to be uncomfortable adjuncts.

Morris (1996) asserts that a 'disabled identity' is male dominated: a perception shared by many disabled women. This 'disabled identity' is externally-created, grown from thoughts, stereotypes and assumptions the accuracy of which is taken for granted; they are seen as natural, positive 'givens'. Not only does the identity arise from unequal power relations, but also it has the effect of reinforcing them. The power inequities are illustrated in the stereotype of disability as a state of dependency, and passivity. It is symbolised in a caring relationship where, traditionally, one party gives necessary care to a helpless recipient (Dalley, 1988, Finch 1984). The giving is in one direction, and there is no sense of a reciprocal or balanced relationship.

Mauss (1990) has explored the dimensions of such gifting relationships, and emphasises the unbalanced workings of power relations displayed in such one-way giving. Such relations are seen in terms of motivation: "What is wrong with the so-called free gift is the donor's intention to be exempt from return gifts coming from the recipient" (1990: vii), and in terms of consequences "the unreciprocated gift [service] still makes the person who has accepted it inferior" (ibid: 65). He makes clear that gifts or services from which no ostensible return is required, perpetuate or reproduce relationships of unequal power. His observations may

readily be applied to a conventional caring relationship, to reveal its harmful effects for many disabled people.

Given the presence of assumptions and built-in relationships of power in 'disability identity' derived from external sources, it is unsurprising if new constructions of disability identity, generated by disabled people, may have been built in ways that echo existing power relationships. Neither is it unexpected that analysis by disabled women such as Morris (1991, 1996) shows that the way identity and power intersect needs to be examined. It is therefore relevant at this point to examine how power contributes to the construction of minority identities.

Power and identity

Conventionally, power is described in relation to how it is possessed and used as a means of control. It is often a political tool. In Weberian approaches, power is invested in the (political) state, while Marxist approaches locate it in the ruling class. Both approaches contain the notion of power as an ability to compel or coerce that is seen as coming from the top down. That is, they look at how it occurs, and how it is manifested.

Freire (1972) deduces the presence of power from its consequences: oppression, inequalities in wealth, health and chances, and an unjust social order that requires an ongoing struggle if they are to be changed. His analysis has a focus on the consequences of power, rather than on its use to compel or coerce, but it is similar to conventional definitions in its understanding that power is a 'top down' state of existence, in which oppressors of either left or right political persuasions dominate and control the country and oppress some groups (1972: 17-18).

Sawicki (1992) summarises three principal assumptions upon which traditional approaches to power rest as, first that power is possessed by a class or by individuals, second that it flows from top to bottom, from a centralised source, and

third that power is primarily repressive, being backed up by sanctions. (1992: 20). Rouse (1994) is even more succinct: he says that traditional approaches to power are built around sovereignty and obedience.

Foucault and Power

An approach which differs markedly from the traditional concepts has been developed by Foucault (1965, 1977, 1978). He uses concepts of power to explain the relationships, disciplinary processes and dominant discourses among a number of states (of being) existing concurrently. Foucault (1978) does not see power as something that is 'had' by those 'on top'. Instead, he says, power is created, and recreated in the everyday lives of most individuals. It constitutes a "complex strategical situation in a particular society" (cited in Champagne 1990: 66). His conceptualisation of power has three key elements.

First, power is seen to be dispersed; it can be found everywhere, and in all situations, not just in large-scale or extraordinary circumstances. In the everyday life of disabled women, it may be seen in a relationship with a home support worker, a front line government official, or a pastoral care visitor from a local church.

Second, power is dynamic, and not an unchanging entity. It exists in relation to a particular social context and changes, just as the networks through which it is exercised change. In the early 20th century, disabled women in institutions were prohibited from any contact with men. At the time there was strong support for eugenic thought, and the belief that 'degenerate stock', who included disabled people, should not reproduce. Further, disabled people were believed to be sexually deviant. Power was therefore exercised in a climate of suspicion and belief in the need for strong social controls.

The current debate about reproduction (and sexuality) for disabled women takes place in a context of genetic counselling, and private control of reproductive technology in which the ability to pay is of high importance. While there is still a high level of anxiety about the birth of disabled children, the context of power has moved to economics and technology.

Third, techniques of power, which describe the ways that power relationships take place, start at a local level and become more widespread or globally used. It means that techniques of power are developed and used in a local setting, then have wider application, then become generic. Foucault calls the process 'swarming'. Techniques to control the sexuality of disabled women in some of England's turn of the century institutions were initially small scale, localised responses, and as required. The process became more generalised in widespread surgical sterilisations later in the century (Buchanan, 1997, Horwood, 1988).

Discourse

Foucault describes discourse as the principal mechanism through which power and knowledge are linked. Discourses, he says, are communication acts, both written and spoken; thoughts, concepts, and patterns of ideas that take place in a particular social setting, and form part of a coherent whole (Weedon: 1989). Discourse sets out what is, or is not 'known' about a state or group, and so it prescribes ways of being in the state, both in the external manifestation and the internal experience. Discourse can shift over time, for instance as it has done over madness[48], so that the way people are treated also changes.

Although discourse is used to control how people are treated, Foucault (1965, 1977, 1978) also shows how the power to control and change does not come from

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[48] When, at the end of the 18th century, the discourse about madness changed from morally deficient and dangerous to the understanding that mad people were ill, ways of treating them changed too. Instead of incarceration and restraint, asylums were established, and mad people were taught new and "normal" ways of behaving , so that they would regulate their own behaviour (Foucault, 1965).

within the group about whom the discourse exists. Discourses about madness have characteristically been produced by non-group members: currently these are psychiatrists, psychologists and other "experts". The people who are "consumers' or 'survivors' are not part of the powerful discourse.

Fairclough (1995) agrees with the linkages between power, discourse and the power differentials that Foucault makes. He points out that discourse is:

> conceptualised both in terms of asymmetries between participants in discourse events, and in terms of unequal capacity to control how texts [written discourses] are produced, distributed and consumed...in particular sociocultural contexts. (1995: 1-2)

Although discourse represents a compelling way that power is exercised, it is not the only way it occurs. Other mechanisms of disciplinary power, or practices exercised on the bodies and souls of individuals are surveillance and examination. These practices focus on gaining knowledge and increased control over the group upon which they are practised. Such practices include prescribing where people can go, at what times, and what actions they can or cannot do, or being always subject to random scrutiny. The exercise of such practices are commonly experienced by any disabled person in an institution or, arguably, group homes.

Concerns

The techniques of discourse and discipline detailed by Foucault are very consistent with actual experiences of women with disabilities, where control is happening on an everyday basis, and changes over time and situation, and practices of control have become generalised. But the implications of Foucault's and post-modern insights into identity contain various problems. McLaren (1993) points out that such insights imply a relativism that is hard to fit alongside concepts of structural inequality, which they seem to deny. An individual's experience of inequality could be seen solely in relation to that one individual and,

McLaren argues, not as set into a wider social or economic context. This effectively trivialises and relativises participants' experiences.

For example, disabled women might each have their own personal experience of disability in relation to, say, poverty. But if disability, and, further, being a disabled woman is seen to exist just in terms of individual experience, that can be used to deny that disability exists outside the individual's mind. The existence of disability or poverty is illusory. So it could be argued that social factors do not exist in their own right and there is no need to address disability at a systemic level. Hence, relativism may be used as an argument to justify no action to address inequalities.

A second and corollary implication of discourse is expressed by Eagleton (1991), who is concerned that "ideology is a matter of 'discourse' rather than of 'language'- of certain concrete discursive acts, rather than of signification as such" (cited in McLaren, 1993: 213). He believes that a focus on the spoken-about component of discourse can, in effect, divert from concrete, tangible effects of discourse such as discriminatory practices. Bhabha (1994) reflects this concern when he asks " Is the language of theory merely another power ploy of the culturally privileged Western elite to produce a discourse of the Other that reinforces its own power-knowledge equation?" (1994: 20-1).

While the approach to power which Foucault develops and particularly the way it can address relations of power at a much more everyday and pervasive level provides a useful way to consider identity, it has been subject to criticism. Prominent among those offering critique are feminist writers such as Hartsock (1990), Cocks (1989) Bordo, (1989) and Butler (1989). They believe Foucault's response does not adequately address the dimensions of power that are built into gender relations, and does not appear to contribute anything useful to a struggle to change discriminatory structures.

Sawicki: Multiple Identities

Sawicki (1992) argues that Foucault's treatment of power is androcentric, but his concept of resistance constitutes a useful approach to power and identity. Foucault (1978) saw resistance as the needed response to domination: "Where there is power, there is a resistance...this resistance is never in a position of exteriority to power" (cited in Sawicki, 1992: 24) The growth of resistance can be seen in they way that disabled women (Keith, 1994, 1996, Begum, 1994, Morris 1991, 1996, Vernon 1996) now recognise their distinctive identity, write about themselves, take themselves and their issues seriously, and form their own definitions of power which constitute challenge to existing power relationships.

The concept of difference is a key feature in the development of Sawicki's (1992) argument about identity. She describes difference as existing within a group and further, within an individual. She advances a "radical pluralism" which "operates with a relational and dynamic model of identity as constantly in formation" and which "recognises plurality both within and between subjects" (1992:8). She asserts that difference does not inevitably mean opposed stances, and uses feminist understandings of sexual identity to illustrate this.

In the struggle to explain female sexual identity, each of two principal stances, libertarian and radical feminists, was convinced that they had the 'right' explanation. But Sawicki (1992) approached the issue in terms of how relationships of power had operated in relation to social identity. She argued that the control, and the arguments about identity were both concerned with the ways that female sexual identity was expressed, rather than with any attempt to control the existence of female sexual identity itself.

Following from this, she has concluded that this siting of struggles over relationships of power is misleading, since sexuality is "itself an arena of struggle"(ibid: 43). To frame sexual identity in terms of a unitary or opposed

identity-either lesbian or feminist is profoundly unhelpful, she concludes, because the debate needs to be about the formation of :"personal identity as constituted by the myriad of social relationships and practices in which the individual is engaged." (ibid: 41).

From this example, the argument that Sawicki (1992) advances is visible: within an individual, as in a group, overall identity comprises a number of different identities. A focus on a 'central identity' or a 'true nature' is irrelevant. Rather there are particular forms of experience which people use to express themselves, in a particular social context, and at a particular time. Sawicki's understanding is of these multiple influences on overall identity, with ongoing change to the way in which they combine. These understandings are significant contributions to the approach to identity which I shall develop in the final section of this chapter.

Finding Identity for Disabled Women

A variety of explanations have been used to incorporate or amalgamate the varied aspects of identity in female and disabled. A starting point was the actual recognition that the two aspects might involve differences for which adequate explanation was necessary. An initial approach was to assume that one particular aspect predominates. Such an approach described disadvantage as occurring "mainly because they're women", or "mainly because they're disabled". The approach similar to the concept of sex-class described by Cass (1978), where women's relationship to their class position is seen as the main explanation

An elaboration of the above concept is double disadvantage or double jeopardy. A variety of titles of articles or publications of the 1980s feature 'double disadvantage' and 'disabled women', for example Lonsdale (1990) Jack et al. (1984), Deegan & Brooks (1985). The approach is more often used by non-disabled women to describe disabled women's identity, and Morris comments on

this approach: "I always feel uncomfortable reading about our lives and concerns when they are presented in these terms" (1996: 2).

The approach has been seen as circumscribed by others. Earlier (Wicks, 1991) I have described how the significance of being female, or being disabled is of varying and constantly changing impact. I argue that it is necessary to use an approach in which both factors are not seen in a static, fixed proportional manner, since to use such an approach effectively understates or overstates the importance of disability, or of gender. In discussing how disability and race intersect, Stuart (1993) also points out that to use a concept of double disadvantage represents an "inadequate starting point", and is one in which "rhetoric has replaced clear thinking" (1993: 93).

Double disadvantage carries three implicit assumptions which are questionable. First, the aspects of 'woman', or 'disabled' are seen each to be unproblematic givens or discrete entities with uncontested boundaries. In the previous two sections, I have pointed to the discrepancy between conventional stereotypes of disability and the realities experienced by disabled people, and the less than satisfactory fit between the new orthodoxies of the social model, and the realities of disabled women. There is also discrepancy between feminist descriptions of female realities, for example Dalley, (1988) and Finch (1984) on caring, and what is experienced by women with disabilities in caring. Feminists have challenged conventional stereotypes of female, and have in turn been challenged by women of colour such as Hooks (1990) Lorde (1984) and Collins (1992) for their white, middle class and heterosexist nature of their alternative visions. All of these images, contested then re-contested, highlight that it is cannot be taken as a 'given' that double disadvantage must constitute two distinct entities.

The second assumption is that there is no crossover, no interconnection between the different aspects of woman and disabled. This belief in two discrete "boxes' is,

I would argue, I have described (Wicks, 1991) the way being female and being disabled exist in a dynamic interrelationship. The interrelationship forms a third, compound state that denies separation out into identifiable proportions. When the interconnection is ignored, it effectively limits or denies the existence of disabled woman in their own right.

Third is the assumption that the power relationships between the two different discourses of female and disabled is unproblematic, and that equal negotiating status for the discourses is present. The asymmetries of power that exist in relation to sex or race are well established. How sex relates to race in terms of power is a situation that changes constantly according to context, but is reflected in the words of Hooks (1990), describing this situation and "waiting to learn from them [feminists]...how it came to be that they were able to surrender the power to act as colonisers" (1990: 151).

In a further illustration, the power asymmetries between sex and disability are well illustrated in the dimensions of the debate about caring. When feminist writers such as Macintosh (1981), Finch (1984) and Dalley (1988), call for residential care for disabled people, they argue that this is so that women do not bear primary responsibility for caring. What is illustrated by this stance is that the different discourses do not exist in unproblematic relationships to one another. The issue is cast in opposed terms, where the rights of one party are seen as more important than those of the other, and it becomes an issue of whose rights are more important, whose power should predominate. The notion of double disadvantage does not cope with oppositions such as this.

Current explanations of female and disability take two main directions. In the first, a stance taken by many disabled women, and exemplified in the writings of Morris (1996), is a notion of simultaneous oppression. Morris asserts that neither disability-based nor female-based analyses are, on their own, enough, and the

impact of either factor cannot be ignored. Rather, she urges that feminism and disability should both become inclusive of the other (1996: 15). But such writings tend to orient to a pre-eminence for the disability aspect, so that it is the common thread running through different aspects. Indeed, Morris is clear that she has "brought the perspective of feminism to an analysis of the experience of disability"(1991: 9).

A focus on the aspect of disability is quite understandable, to disabled women. Keith (1996) writes how :

> Disabled people have to work continually against destructive forces...It seems that no matter how cheerfully and positively we attempt to go out in the world, we are bound to be confronted by someone whose response...leaves us feeling powerless and angry. (1996: 70)

But to focus on one aspect of overall identity because it is so strongly present, but less strongly represented is not always adequate. There is still a sense of majority-minority parts to identity, which subtly undermines the part that other components play, and tends to avoid the issue of how the components continually interact.

In a second direction, a feminist perspective, supported by writers such as Munford (1997) and Hillyer (1993) suggests that a base perspective of feminism needs to be informed by disability. Munford argues it is necessary to "begin with an acknowledgment of both the 'difference' and commonalities between women. The struggle must include a celebration of the lives of women with disabilities" (1997: 43). However, in common with a disability infused by feminism stance, a feminism infused by disability stance is an understanding of limited value.

Munford appears to acknowledge this limitation in commenting that "social change processes for women with disabilities will intersect with the struggles of people with disabilities and with non-disabled women" (ibid: 48). Morris also reflects the inadequacies of majority-minority explanations when she notes that an adequate

way of conceptualising disabled women has not yet been formed. She further points out that a framework has not yet been built in which there is "a political and research agenda that reflects our concerns" (1996: 15). I argue that a different approach is necessary, and begin to develop this in the next section.

Reconstructing Identity

Identity and Pluralism

I have argued that the above explanations are less than adequate to describe identity for women with disabilities, and that a framework identity that is adequate to female and disability can be drawn together, from the ideas developed by other writers, notably Sawicki (1992), Hicks (1988), and Bhabha (1994). What all of the different ideas have in common is a sense of drawing elements together to create a sense of whole without disvaluing the constituent parts. Eco (1987) describes the blending of discrete, seemingly disparate elements into a whole that works together as "the very essence of syncretism" (1987: 104). The drawing together of the components of overall identity has this approach to wholeness, although pluralism and identity have, in addition, an implication of fluidity, and a response to context.

To consider identity or the stories we tell about ourselves cannot be an interior journey devoid of the exterior circumstances that shape us. McLaren (1993) reminds us that market forces are now of such dominant influence throughout the world that "we have become the wardens of our own souls through the global logic of 'consumer sovereignty'" (1993: 202). Within this global system, McLaren adds, the gulf between haves and have nots, between wealthy and poor has "widened vertiginously" (ibid, 202).

Because of the overwhelming impact of such global systems, marginalised people are telling their lives, and shaping their identities with immense influence from social circumstances. The 'outside' influences have characteristic influences on

groups of people, although individuals within a group will experience the impact to varying extents. In this section I consider identity in a both group sense and an individual sense, as Sawicki (1992) has done for female sexual identity. I intend to focus at a group level, to draw out factors that can be used to make sense of identity at an individual level.

Border Identities

Writings about marginalised or dispossessed groups can illustrate both sides of McLaren's 'vertiginous gulf'. Hicks (1988) describes this happening in the settings of border narratives, which articulate tensions and wholeness that arise from living in very disparate worlds concurrently. She advances a concept of border identities, and their realities in terms of ambivalence and marginalisation as the " kind of realism that approaches the experience of border crossers, who live in a bilingual, bicultural biconceptual reality" (1988: 49).

Border crossers are migrants who cross the border between Mexico and the United States of America, in order to work in California. While these people retain their primary identification with the Spanish language, Catholicism, and Mexican culture, they need to exist within a different language, culture and value system: mainstream America does not appear to value or respect their differences. The emphasis is on their identification with American language, values and culture. Existing in two different 'worlds' concurrently thus requires ongoing alterations within an individual's overall identity to fit with the context.

What is significant about the concept of border identities is the way that both contexts are present concurrently, so that the complexities of identity formation can be seen. The changing nature of border identities is reflected in the genre of border writings. Deluze and Guattari (1983) point out that change and context are present in these writings, but their importance is also in the way that, as more border writings are produced, the issue becomes more important. I have argued, in

a similar fashion, that such invisibility constitutes a barrier to identity formation for disabled women.

The concept of border identities is, in the first instance, descriptive of a particular way of being; it lays out the way that multiple voices are present within an individual from a marginalised group. It is a concept that has been adapted and developed by many indigenous people in Central and South America, who also constitute a minority within a majority. There, it takes the form of testimonio. These semi-autobiographical testimonio, such as *I....Rigoberta Menchú: An Indian woman in Guatemala* (Menchú, 1984) give expression to what Bakhtin (1968) and Garcia (1994) call heteroglossia or multiple voices within a text about a single individual.

In addition to describing a state of being in different worlds at the same time, Hicks points out that the concept of border narratives also functions as a tool of change. It " hints at the subversive nature of this writing [border narratives]" (1988: 50). Border narratives enable new forms of information and ways of understanding identity to emerge-understandings that are outside of the conventional constructions, and the power relationships they entail.

Border identities thus imply an attitude to power, because the concept challenges or subverts the conventional discourses. García (1994) is similarly unambiguous that the testimonio functions "first and foremost [as] part of political struggles"(1994: 152). Bhabha (1994) is even more insistent that:

> What is theoretically innovative, and politically crucial is the need...to focus on those moments and processes that are produced in the articulation of cultural differences. These 'in between' spaces provide the terrain for elaborating strategies of selfhood-singular or communal. (1994: 1)

Border identities, and the narratives they engender clearly echo Foucault's concept of resistance and challenge to the dominant discourse.

Partial Identifications: In Between

Hicks (1988) presents an understanding of border identities as marginal, and constituting critique or challenge to existing power relationships. This is consistent with the writings on identity of Bhabha (1994), who begins from a belief that:

> The key was not merely in the sociological or the historical verities...but it had to do with the very form in which one constructs one's identities *through these partial identifications.* (1994:189, italics added)

To Bhabha, as with Heidegger, the boundary[49] is a place where something begins. It is where different aspects of identity are not addenda at the end of some other 'real' identity. Instead it is a space where the realities come together, to initiate "new strategies of selfhood" and "new signs of identity" (ibid: 1).

Bhabha rejects the notion of identity that arises from a base of Western individualism, with its corollary of a single 'right' identity. He asserts that such a notion of identity is inadequate to describe the complex realities of those who live in two or many different and concurrent realities. Rather, he describes identity as:

> a scenario, or a circulation of meanings, values and positions, identity as being an illusion of totality, yet that illusion, that ambivalence within identity can be strategically, historically, socially deployed. (1994: 192)

Though Bhabha does not believe in the notion of identity as a unitary concept, he mistrusts the idea of multiple identity. He feels it gives an illusion of "pluralism as if there are many identities to choose from" (1994: 196). The implication is that one can choose to be female, or disabled, or black, or old at a given point in order to extract the maximum advantage from a situation, but he rejects this position. He goes on to point out that such choice implies an opposition to some other identity,

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[49] Heidegger (1978) describes a boundary as "not that at which something stops but, as the Greeks recognised, the boundary is that from which *something begins its presencing"* in *Building, Dwelling Thinking*

and " how do you constitute a set of identities, or a range of identity which does not locate you principally in one or the other?" (1994: 197).

Bhabha's opposition is to a notion of multiple identities where the underpinning notion is of dualities, the capacity to choose an identity which is seen to fit a particular set of circumstances. In this, his notion of identity does not conflict with that of Sawicki (1992), since both envision identity as a constantly re-constituted process, rather than a series of positions to choose from.

Like Hicks (1988), Bhabha believes that constructing identity via partial identifications has a subversive potential. He argues for the "possibilities of being, somehow, *in between,* of occupying an interstitial space" (1994: 1990). Not only does such a state of being make sense of the reality of so many who live lives of many identities, by giving value to all of them, but also it constructs identity in a way that is removed from the existing relationships of power where victim and oppressor are opposed. It is a way, Bhabha argues, for those who are oppressed to instead be empowered "by being able to use these ambivalences and ambiguities, instead of representing power as a kind of homogeneous hegemonic block." (ibid: 190). For them, the identity that is being constantly re-created thus becomes a powerful weapon. Far from being the route to a morass of relativism, it becomes instead a vantage point from which the status quo may be viewed with a clear eye, and given authentic challenge.

Framing identity in terms of multiplicities, border identities or 'in between'; partial identifications has much to recommend it. Above all it addresses the intricacies of being in a number of worlds in a way that makes sense of them, and gives full significance to power relationships. It has a larger vision of identity, which can form and reform its constituent parts, according to the circumstances. It treats the external forces that shape and re-shape power relationships as crucial to identity.

The concepts of power informing the alternative orthodoxies tend to be top-down, so that intergroup power relations, such as between women and men with disabilities, are not addressed by the respective parties. The alternative approach to identity that I present here operates through acknowledging differences, presenting a means to address the unaddressed relationships of power. In short, postmodern based approaches to identity offer greater opportunity to women with disabilities to be themselves, defined by themselves, in their own world, rather than being an "Other" to some other identity.

To be able to put together an identity which fits with personally experienced reality is highly significant for members of marginalised or oppressed groups. Tierney (1993) writes "the force of society as exhibited by our institutions is not toward human freedom and liberation; rather ideologies tend to silence those individuals who do not fit within the norms of our culture (1993: 129). That means identity constitutes a vital aspect of change and challenge to existing power relationships. Snow (1992) adds, "There usually comes a time in the lives of people who are living on the margin when they are prepared to risk giving up their identities as outcasts to try to become participating citizens of the community" (cited in Pearpoint, 1992: 126).

The approach to identity that I have presented here requires further elaboration to address issues which include societal and political implications. The belief that living 'in between' can result in greater diversity and changes to the relations of power is attractive to many women with disabilities, but there needs to be more tangible demonstration of the theory in action.

One way that this can be operationalised is in the relations of research production, so that ways of doing research and using the information generated by it are consistent with a belief in multiple identities. The following chapters, on research methodology, display of the women's stories, and discussion of the themes that

emerge build from the basis of this review of the literature. In doing so, Appiah's (1991) description of theory as about living in particular ways rather than just seeing the world in different ways: being part of both the doing and the being is affirmed. The methodology also addresses the challenge implied by Marx's words about changing the world rather than simply describing it. To 'do' requires a sound plan.

METHODOLOGY: FROM THOUGHTS INTO METHODS

This chapter discusses how the stories of women with disabilities can be told appropriately, and what happens during the process of telling. In the previous chapters I have laid out the process of oppression of disabled people, showing a sequence of negative thought into negative images, and thence into disadvantaging acts and imbalances of power. I have elaborated on the way negative attitudes and images have come together into a dominant discourse about disability. Among the consequences of this discourse have been that the voices, stories and experiences of women with disabilities have been silenced; they have not spoken for themselves.

There are implications for research methodology in the components of the dominant discourse, notably in medical models. The opening of this chapter therefore examines the consequences of using a medical model as a theoretical basis for research design and practice. Likewise, this chapter points out some of the limitations of the 'alternative' orthodoxy of socio-political models of disability for research methodologies.

In the previous chapter, I discussed the formation of identity, and suggested an approach to identity that draws together ideas from post modern writers such as Bhabha (1994), Sawicki (1992) and Hicks (1988). A theme common to these writers is how overall identity comprises the coming together of different identities which exist concurrently, and the power to explain that it contains. Bhabha (1994) describes this "in between" nature of identity as constituting a challenge to orthodox concepts of identity. The implications for methodology are in the use of methods that are consistent with this insight.

In this chapter the aspects of theory and methods are present to varying degrees at different points. The chapter is in five sections. The first section presents an

outline of four key components of methodology: theory, methods, relations of power within research, and values and their relationships. In the second section I discuss ethical issues that can arise in the research process. This covers a number of different points such as how questions are generated, what consent includes and use and control of the material that is generated. A third section considers research methods in relation to appropriate practice, particularly the difficulties that conventional relations of research production impose. The difficulties are set alongside an overview of suitable approaches such as oral history. The fourth section draws together the material of the preceding sections to specify methods chosen for this project, including features of consultation and participation. The final section comprises a reflection on process issues which arose during the interviews and how the issues illustrate methodology, ethics or contradictions.

1. KEY COMPONENTS

Theory and Methods

There is no clearcut boundary line between theory and method; both impact on and modify each other. Tierney (1993) highlights this interconnectedness, remarking that "theory and method act in a dialectical nature, with policy and practice" (1993: 2). His comment is consistent with that of Appiah (1991), who describes theory as part of both being and doing, so that theory fits with practice in a particular context.

Combining theory and method is thus about a good fit, or making connections. In this research the theoretical stance is grounded in power relations: the way that thought constructs images, and practices, and the silences that result from this. The theory is also concerned with identity. I have argued that identities which are conventionally seen as disjointed can, because of the differences they contain, become an alternative source of power.

In choosing methods, emancipatory research, which involves giving voice and power back to the silences would constitute a good fit. But a good fit involves more than consistency between theory and method alone. Particular fit of methods to a group's situation is also needed. For example, the use of consultation first to find whether the research was a priority for disabled women then the use of audiotaped narratives both illustrate appropriate ways to respond to their experiences of marginalisation. It is similar to the 'micro fit' used when Maori researchers work with Maori. Mutual and acceptable contact people from within the appropriate tribe, hapu or whanau is commonly required for the fullest possible information to become available (Parekowhai, 1992). Appiah (1991) suggests, the interplay of theory and practice that constitutes methodology is inevitable, and further, it takes place at a number of different levels concurrently.

Power

Relations of power are a theme throughout this thesis, reflecting their central place in the everyday experience of disabled women. In overall terms they can be seen in the way a discourse about disability that does not arise from disabled people is able to predominate. It is further seen in what happens when the discourse is used, and in the results arising from it. Power, and its relationships, influences theory, method, and the products or outcomes of the research project. Power relations are present in methodology, and at any other point in the research process in different ways and to different extents. Since I have taken power as an inevitable component in the research process, the point is to recognise its presence, its consequences and how it is to be addressed.

An illustration of how power relations occur repeatedly during research processes is in the 1986 Survey on Disability undertaken by the British Office of Population,

Censuses and Surveys (OPCS)[50] Power relationships are first seen in the theoretical base of the survey. The research is grounded in the orthodox discourse about disability, built up over the previous centuries by spiritual leaders, temporal rulers, administrators, carers and relatives. The discourse is largely negative and deficit centred. Disabled people appear to have a less than equal status commensurate with that understanding

Oliver (1990) describes how the questions in the OPCS survey were deficit focussed, shaped by the dominant discourse, and had the effect of reducing the issues to "personal inadequacies or functional limitations" (1990: 7).

When it came to the choice of participants, power was again significant. The disabled people who were the subject of the OPCS research may well have felt they had little choice but to participate. This feeling of relative powerlessness, occurred because the government which sponsored the research was also the source of such items as home support, housing, equipment or personal assistance. So a compliant response to ensure continuity of their support arrangements would not be unusual[51].

The interviewer visited each individual alone, in their home, asking set questions in a set way. Oliver (1990) describes the questioning as a process that was

> Oppressive, reinforcing onto isolated individual disabled people the idea
> that the problems they experienced in everyday life are the direct result of
> their own personal inadequacies or functional limitations. (1990: 8)

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[50] I have drawn from the articles by Abberley (1992) and Oliver (1990) in discussing this topic. I have specified stages in a research process which are common to research processes, but which were not explicitly mentioned in the articles. For example, this chapter will describe the influence of theory on method, the questions asked, the manner of asking and use of the results.

[51] Anecdotal evidence in Aotearoa/New Zealand suggests that where an activity such as a survey appears to be sponsored by the provider or funder of services, disabled people will commonly cooperate with the activity, so that they are able to maintain their service.

In the OPCS survey, considerable data was gathered, but the use of the data is open to question. In his critique of the survey, Abberley (1992) says the data was gathered in a questionable way, as outlined above, and for equally questionable purposes. But the results of such research gained wide currency, substantially because of they came from authoritative and powerful sources. Critique of the results, produced by the Disability Income Group (DIG) received little serious discussion. Such seemingly authoritative can be cited in a number of publications, including journals, books and the publications of other government agencies. They can be used in policy papers, even to support laws or regulations. Here the power of the sponsoring agency constituted an effective buttress for the results.

A last reflection on the relations of power in such research is that the results may well be accepted by disabled people themselves as an accurate representation of their position, since it gives the appearance of being authoritative. The end consequence of research such as the OPCS surveys may be that the relations of power are perpetuated and the dominant discourse is effectively reinforced, including among many disabled people.

A similar critique of the uses and effects of power informs writing on feminist research[52]. Reinharz's (1992) list of the ways power is seen includes the impact of patriarchal theorising on research questions, the use of methods that alienate women from the research process, and the non-participation of women in the research process. In addition to identifying the points where power relations are seen and changing the relations, feminist research often develops methods which counter the presence of power, for example using role plays developed to explore girls' attitudes to their gender (Griffiths, 1995).

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[52] Here feminist research is used in Reinharz's (1992) sense of a perspective on an existing method, or a perspective that can be used to develop a new method.

Values

The place of values in methodology needs to be acknowledged. Values represent an individual judgement of what is important and may affect the methods used. Two individuals may hold a very similar theoretical stance, say on post-modern approaches to identity, but one individual's values may be grounded in Marxism, the other in a God-based spirituality. They may have a common desire to use action research methods. But one's values for participation may be expressed in a group emancipatory project, while the other's value for dignity may require confidential open-ended interviews.

In this project, I aimed to construct a methodology that demonstrated participation, and collaboration for the disabled women with whom I talked, because I value direct self representation, collaboration, openness and equality in the research relationship. I further did not wish to compromise the values of the disabled women. These values needed to be reflected in the way I conducted the research. For example, I visited Sophia, an hour's drive away, to record an interview, and found, on my arrival that she was unwell and exhausted. She knew about my chronic tiredness, exacerbated by travel. She also had values including sharing and equality in relationships, and thought she would talk despite her ill health. We discussed the matter together, and reached a shared decision to reschedule the visit, a decision that fitted the values of us both.

2. ETHICAL ISSUES

This section examines ethical issues that arise when constructing methodology, and at other points of the research process. These 'other' points are the interface with the 'host' community, participation in the research process, consent and the uses and ownership of the information that has been collected.

Two central ethical concerns identified by Dodds, Albury & Thompson (1994) are respect for all persons, and justice. They elaborate that respect for persons, involves recognising and upholding their dignity, autonomy and right to make choices, and justice involves fair treatment for all persons, and point out that these concerns recur at all points of the research process. These concerns are consistent with the principles of emancipatory research; reciprocity, gain and empowerment (Oliver 1992). Both sets of concepts are concerned to address disadvantage and powerlessness, which means they are relevant to the experience of disabled women.

Dodds et al. (1994) further distinguish between those considerations which are intrinsic to the research, and those which relate to a researcher's integrity or professional standing. I argue that the term 'professional' needs to be used in its broad sense, to include standing, mana or credibility within a community. By extending the coverage of the term 'professional standing', there is recognition that a marginalised group often has more diverse ways to recognise community standing than job status.

For example Maori or Pacific Islands cultures often accord great standing to elders or leaders whose prestige does not derive from their seniority in paid employment. A broader sense of the term effectively gives recognition to a group by respecting its priorities. To me, as a member of the community of disabled women in which I am also conducting research in, my credibility is of immense importance. I understand that it was, in some part, responsible for the support for the research project. It is important that I, as the holder of such credibility, do not replicate bad research practices which could have the effect of disempowering my community.

Constructing Research: Epistemologies

I have described the way in which theory and methods come together to make up a methodology. There is a further dimension to ethical concerns in the use of

epistemologies, or theories about knowledge, and how the knowledge(s) becomes known. For example, a scientific epistemology is based around observable, testable, 'facts'; a disinterested pursuit of knowledge (MacNeill, 1993). But science and scientific research does not adequately deal with a number of issues in social science such as ostensibly 'neutral' enquiry, or power relations in research production.

Alternative epistomologies thus emerge from different ideas about what counts as knowledge, such as cultural, gender or marginalised knowledge, or through the ways of knowing it, such as experientially. To develop and propose such alternative epistemologies means different people may become the people who 'know'. It is in this sense that Harding (1987) has described feminists as proposing "alternative theories of knowledge that legitimate women as knowers" (1987: 3).

When the alternatives develop into projects based around epistemologies from groups who were previously marginalised, such as disabled women, placing them as 'knowers', they constitute a challenge to established epistemologies (Dodds et al., 1994). The important point here is not which epistemology is 'right', but that the ethical concerns and epistemology are appropriate to the group being researched, to their ways of knowing. In this project, open affirmation and ownership of their own stories, their own lives, effectively the status of disabled women as knowers has been a key point, so ethical concerns associated with other epistemologies were not as appropriate.

The 'Host' Community: Partnership, Participation

Participation occurs in two ways. In the more usual sense it is about 'doing' the research, for example to produce interview tapes or complete a written questionnaire. In the second sense, it is about taking part in decisions about the project on an equal basis: on the research topic, on the questions, on use of the

information. It is this second sense of participation, Zarb (1992) says, from which disabled people have characteristically been excluded.

I saw that attention to the latter sense of participation would provide a more consistent ethical approach to the former, and incorporated participation mechanisms in two ways. First in a preliminary, consultative phase, the possibility of such a project was discussed informally among some community members. When I formulated a more specific research project, I again discussed the idea with a number of women with disabilities. Support for the project was unequivocally positive. I was often urged to begin the project 'now', or to record more women, and 'soon'. Through attention to participation from the beginning, I established sound processes that acknowledged the community I wished to research in, and ensured I would ask about issues of importance to them. Second, when the research project became active, I drew together a reference group of disabled women with whom I discussed concepts and questions as required. They served as a further avenue for me to discuss the way I shaped the question areas.

Consent

Informed consent has no single, unambiguous set of boundaries. It is common throughout Western or non-indigenous research that consent comes from an individual, and the notion is concerned with upholding her or his privacy and autonomy. Individual consent is also predicated on its being informed. Dodds et al. (1994) point out that there are boundaries to consent based around an individual's perceived competence to understand and to agree (1994: 62). For example, people with some psychiatric intellectual or cognitive disabilities may be perceived as incompetent to consent.

In contrast, indigenous communities may view individual consent as inappropriate, as they see that information or stories belong to a community, which needs to consent to participate in a research project. For example, when Soutar's Maori

Battalion Oral History Project recorded stories from the C Company's soldiers and whanau in 1995-6, most communities in the areas concerned held hui to reach agreement to participate before individuals were interviewed. Here individual consent derived from community consent.

Neither of these perspectives alone was entirely appropriate to the situation of disabled women, but I have incorporated elements of both in my project. As a community, disabled women are largely unaware of the life stories of members, and there are few systematic opportunities either to share or to access them. For example, I may be one of the few disabled women to whom Sophia has talked about her qualifications in marine engineering. But in telling me, she was speaking to other disabled women through me. She shared individual information for community purposes: I suggest that she implicitly recognised a sense of responsibility to it. In this situation, being able to own their (our) own stories, to have them known to other disabled women, to be recognised as being a 'knower' and as a member of a community which holds valuable knowledge are important parts of breaking a silence.

I argue that individual consent and community agreement are both important factors in informed consent. In this research, conventional anonymity would not be an appropriate ethical standard as it would serve only to perpetuate the silence of the disabled women. Being known and named affirms the stature of the knowledge, and of the knowers.

I did not intend that informed consent should be simply a matter of obtaining a signature on a consent form. This is based on a description of informed consent (Dodds et al., 1994) as a more ongoing process that includes agreement to participate, agreement over the process, and on the use of information. I therefore

used a staged process of consent that began with an information sheet, available in accessible formats[53], and supplemented by discussion with each woman.

When the time came to interview, each woman was invited to sign a form of consent to participate in a recorded life history interview. Once the life history and any subsequent discussion was completed, the woman was again invited to consent to the use of tapes and storage of the tapes under nominated conditions of access. The acceptability of conditions of access in storage was again checked when transcripts of the interviews were sent to each woman for checking.

Two particular concerns were addressed by this process. First, I wanted the disabled women to have more than one opportunity to consent to the process. For disabled women to exert control within the research process has symbolic and real significance, as it runs counter to the many aspects of control by others in the lives of disabled women; for example using personal care or home support services. Second it recognises the different points at which control is asserted. It is not just in generating the information; control also exists over the storage and use of the information. Such a staged process of agreement specifically addresses the relations of power in research which can be, as Oliver (1992) points out, so unbalanced and corrosive.

It is a salutary experience for a researcher, at the completion of an interview, to recognise that their partner has the right to terminate the process. Dodds et al. (1994) report that some interviewers hand over all the tapes as soon as an interview is completed, then ask for them back. The sense of a lack of control in both situations is a clear reminder of how often interviewees feel a lack of control

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[53] Accessible formats present the information in a way that is best for a woman's need to 'read' the information. They include disc, brailling, large print, font, background colour or tape. Because disabled women require a variety of ways to obtain access to information, the use of a variety of formats and where what disabled women require is ascertained as a matter of course signifies inclusion.

over the process and demonstrates that the researcher takes the concept of partnership seriously.

The information: who uses it, who owns it, what happens to it

A positivist perspective frames the information generated by a research project as the product of unproblematic relations of research. In opposition to this, Oliver's (1992) critique, describes the information arising out of research as most often removed from the control or interests of disabled people. For this reason, I engaged in active partnerships with the disabled women who participated in the research. Lincoln (1993) describes such a partnership where:

> The silenced who agree to participate in research must also be willing to take several and profound risks of acting as collaborators in this research. This will mean, at a minimum, a dialogic partnership of equal involvement, in...conducting analyses of data alongside social scientists, and outlining, framing, writing and assenting to the narratives and texts which represent their lives. (1993: 42)

Since the product of the interviews is an audiotape, I have negotiated control over the tapes to be divided among three groups of disabled women. First, the narratives are jointly owned by each individual woman and me in my role as researcher. Second, I am able to use the information so that I can complete this thesis, and any associated publications. Other use, by me, or by other researchers requires further agreement from each individual woman who has been interviewed, and myself. Third, the originals of the tapes will be stored at the National Oral History Centre in the Alexander Turnbull Library. Written agreement to this storage was obtained from each participant. The community of disabled women, as a whole will hold responsibility for additions to, the disabled women's archive.

3. RESEARCH METHODS AND APPROPRIATE PRACTICE

In this section I describe three of the more relevant approaches to disability research, so that the reasons for my chosen method becomes clear. I begin with a brief summary of two other, more conventional approaches: positivism, and an interpretive approach. I then describe the approaches contained within the grouping of emancipatory approaches. I have included oral history within this grouping since it is, at its core, concerned with social change and power (Frisch 1990), and highly consistent with an emancipatory approach to research.

Positivism

Positivistic research derived from the 19th century efforts of August Compte (1798-1857) to use scientific methods to enquire about the social world. Rigorous scientific enquiry in the manner of 'hard' sciences such as chemistry was extended to a social sphere. Social science research was expected to show how the laws of society could be discovered. Its practices involve hypotheses, deductive logic, testable and measurable results, and clear, scientifically determined definitions which are seen as universally valid. Positivistic researchers use such methods in their experiments that could be replicated by others; usually this means using quantitative methods. Above all, they see themselves as detached, objective, and in charge of the process.

Among the negative consequences of a positivist approach, alienation has been clearly identified. It is a separation of the individual being researched from the research process, and from its product. Oliver (1992) describes a research process which produces alienation as one in which disabled people "come to see research as a violation of their experience, as irrelevant to their needs, and as failing to improve their material circumstances and quality of life" (1992: 105).

A second consequence of positivism is that it reinforces or increases asymmetric power relations. Asymmetric power relations are described by Mauss (1990) as

present in gifting and exchange relationships. Gifting, he says, is a mutual exchange of tangible items or ideas, and includes acts of talking or listening. In such symbolic acts, humans interact with one another, and aim to maintain reciprocity and balance in the interaction. But in positivist research, the gifts of knowledge or information are likely to be seen as of unequal value. The giver whose gift appears to be of considerably less value, finds they cannot experience balance from the exchange. Participation on equal terms, and the apparent worth of their gift seems to be effectively denied. The denial further can imply that the individual is less valued as a 'knower', a carrier of worthwhile knowledge.

A third limitation of positivist research is that it does not acknowledge the impact of values. Freire (1972) observes that an entity called 'neutral' education does not exist, and the 'phrase 'social enquiry' can be substituted for the word 'education' with no distortion of meaning. Guba and Lincoln (1989) support this, remarking:

> we know that facts are theory laden, that they exist within some value system, and that, therefore, they are themselves embodiments of a value position, however hidden beneath 'scientific discourse' terminology. (1989: 123).

In disability research then, what questions are asked, and how they are asked are fitted around the dominant discourse of disability, and the stereotypes and values it contains.

A final limitation of positivist research in the disability arena is that the information produced is seen as unproblematic, so that "given the facts, government will act, and changes will occur" (Oliver, 1992: 109). But the inevitability of this sequence is by no means certain. For example, although government has collected statistical information about the extra costs of disability, and the extent of unmet need among disabled people[54], no policy changes to respond to these circumstances are anticipated. There is no inevitable relationship between research of any kind and

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[54] Tables 57 and 58, Statistics NZ (1997).

policy change. But the perceived capacity of a positivist approach to research to engender change, can be questioned.

Interpretive approaches

During the last thirty years, a number of writers in both natural sciences (Kuhn, 1961, Popper, 1972) and social sciences (Giddens, 1979, Hindness, 1980) have queried positivist assumptions and methods[55]. From such questioning, Oliver (1992) notes the evolution of a new approach in both assumptions and research methods. This interpretive approach sees knowledge as socially created, arising out of a particular context, and says research and the methods used should be aimed to understand what events mean (1992: 106).

The interpretivist approach can also be criticised. Oliver is among those who question the value of this approach. He comments that "while the interpretive paradigm has changed the rules, in reality it has not changed the game" (ibid: 106). Feminist researchers have also questioned the approach, saying it encourages 'research rape' (Reinharz, 1985). In disability research, such plundering also occurs. Researchers, (most often non-disabled) record events and decide what they mean to those disabled people concerned. They then move onto other, usually more remunerative) research, while those who were researched remain in the same situation, and the research has instigated no change.

Emancipatory Approaches And Speaking Silenced Lives.

Emancipatory approaches in research have grown out of dissatisfaction with positivist and interpretive approaches. At the centre is a recognition of the part power plays at all levels of conventional research. Feminist research, notably standpoint research has developed methodologies that are consistent with an emancipatory approach (Harding, 1987). Within critical theory, a number of

methods based around telling stories and naming silenced lives have developed, and they are also consistent with emancipatory approaches. Oliver's (1992) contention that disability research must be based in "recognition and confrontation with power which structures the social relations of research production" (1992: 110) thus sits comfortably with an emancipatory approach and enables challenge to the social relations of research production, that can re-define " the real nature of the problem" (ibid: 112).

The key principles of emancipatory approaches are, according to Lather (1991) reciprocity, gain and empowerment. Given the disempowered position of disabled people, it is unsurprising that empowerment has considerable significance in disability research. Le Compte (1993) says it is not sufficient simply to set up a situation in which silenced or marginalised people can tell their stories. She continues:

> If researchers truly wish to empower those whom they study, they must redefine informants to be those *with* whom they study....Empowerment is not just a discourse or a state of mind. Empowerment requires the acquisition of ...power and its exercise....That vision cannot simply be the construction of a text to be published. (1993: 14)

This statement is consistent with Oliver's (1992) point that empowerment is not a matter of a few researchers delivering a gift, but concerns the way research can be used to facilitate the process when people decide to empower themselves.

Oral History

Le Compte's (1993) comments above on empowerment supports the use of telling stories as a method of choice. Similarly in disability research, telling stories has considerable support as an appropriate method (Ballard, 1994, Munford, 1994,

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[55] Such questioning of aspects of positivism does not mean that one was therefore an interpretivist. Popper, for example, developed a particular view of scientific methods although questioning certain of its assumptions

Booth, 1996). Hence I have chosen to use story telling to enable discovery and analysis.

From the number of ways of telling stories, I chose to use oral history. It can act as a tool through which people can understand changes and events in their own lives (Thompson, 1988). It further has a capability to collect, articulate and display stories, and it is a tool for transformation, which can take place at a social as well as an individual level. Arguably its most powerful characteristic is that it takes a 'bottom-up' approach, recording the stories of 'ordinary people'. It has the capacity to bring out information about marginalised groups, and enable them to talk amongst themselves.

Oral history has been used in a number of research streams, such as ethnographic, or feminist research. It is very appropriate to use in research with disabled women. Not only can it be used to interrogate, or challenge the images of disability that are embedded in the dominant discourse, but also it is a means by which multiple identities can be explored; as components, as interrelationships, as part of an overall identity. Tierney (1993) has noted how the lessons of post modernism on multiple identities can become remarkably concretised into "me, all of me" (1993: 131).

Oral history came to attention through being identified as a somewhat 'substitute' research method used by historians to collect the life stories of groups of people or communities who traditionally were sparsely represented in conventional history. It became used in diverse forms and by various people: feminists, sociologists, indigenous people, ethnographers, disabled people, educationalists, social policy analysts, trade unionists. Frisch (1990) articulates a more developed understanding of the uses and scope of oral history where the method comprises "a challenge to all the assumptions of conventional scholarship, a way...to

challenge the established organisation of knowledge and power and politics" (1990: xviii).

Consent Revisited

Among the conventional practices of oral history is the acknowledgment that a named individual has told her story. Anonymous stories are not usually found in oral history: just as anonymous autobiographies are not usual in conventional history. To acknowledge in public the ownership a disabled woman has of her own story is highly appropriate in this research, which has an open intent to tell the stories of disabled women. Unless we can name our own lives, and honour our own stories, change to the dominant discourse, and the marginalised position of disabled women will be hindered.

Textual Appropriation

Oral history largely avoids a problem of disability research: the textual appropriation that occurs when one individual assumes the ability to speak on behalf of another individual, and in their interests (Opie, 1992). In disability, this can happen when parents, family or unpaid carers assume a spokesperson role where they 'know' what is best for people with intellectual disabilities', or decide that women with intellectual disabilities would best be sterilised, or informal carers find themselves called on to define what a head injured or demented relative needs, wants or would say.

In such circumstances it may not be apparent whose perspective is being represented, or to what extent. The carer for (say) a demented individual will have entirely legitimate needs, but their views and needs can be seen to be an accurate proxy for the views and needs of the disabled person. In these circumstances, textual appropriation and power imbalances can occur.

The possibility that textual appropriation may occur is minimised by the orientation towards the story being told by the individual about themselves, and their own perceptions and in their own way. Oral histories are almost never occasions where one individual tells another person's story and perceptions. The occasions where this takes place are concerned with some form of interpreter services, to relay what the person being interviewed wishes to say. This may, for example, be where it has been agreed that a deaf person who signs will have her or his story recorded on audiotape, or where an individual's indistinct speech is relayed. The key point is that the story is relayed directly from the individual being interviewed: the text is theirs to shape as they choose.

In my research, textual appropriation was a potential rather than actual threat. The disabled women with whom I conducted interviews, welcomed the oral history method used for its responsiveness, and expressed few doubts on their ability to talk for themselves[56]. Similarly, there were few problems of getting past those who might wish to 'speak for' a disabled woman; the women were all independently circumstanced independently of the gatekeepers who might wish to 'speak for' them. However concern for the potential difficulty that textual appropriation poses remains valid in this, and other emancipatory research.

Research Roles: Who says, Who interprets

This thesis contains two, related premises. First that there is no single right knowledge, no single version of reality. A corollary is that there can be a number of different readings of an event or ongoing situation. Second that these understandings become gathered into a discourse, in its Foucauldian sense, and one discourse becomes recognised as the orthodox or real version.

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[56] One woman who did express doubts about her ability to talk did so because she had a speech impediment. The doubt was more concerned with practicalities than whether the method was, or was not suitable

I have also argued in this thesis that the ways disabled women experience their lives differ considerably from the dominant discourse about disability, or discourses about being female or old. Disabled women have a different discourse, a different experience, and to hear this requires listening of the right kind. If hearing, interpretation and control have been with others, then research roles within a project should pay a careful attention to the power relations if an alternative discourse can emerge.

An orthodox conception of a researcher's role apportions control to the researcher, who conceives the aims and objectives, designs the method, asks the questions, analyses the results and decides what is to happen to the information collected. In my research, I have chosen to re-conceive most of these functions: I agree with Lincoln's (1993) observation that "researchers face a new set of imperatives in conducting research on the silenced" (1993: 32), and have acted in accordance.

In the previous chapters I have joined the voices which challenge the dominant discourse on disability. But further, I have questioned the way in which alternative orthodoxies of a disabled women's identity have been conceived. In addition to this challenge, I have laid out the basis of another reading of identity. The question of what constitutes the research role is therefore significant.

In developing the way such roles of researcher and researched-with relate to each other, I have used the dimensions identified by Le Compte (1993). They include the use of alternative and appropriate methods, that knowledge needs to be produced owned and shared by all people, that researchers need to use open practices that do not minimise differences, that researchers seek out stories and faithfully reproduce them: not just the stories, but also the way in which the information was generated.

A final consideration in this section is that I am a clearly identified member of this community. Rather than reviewing the ongoing debates on whether a researcher should, or should not be an insider, I will focus on two key aspects of undertaking research as an insider.

First, to have another disabled woman conducting the research sends an implicit message of respect. What is understood by the action is that the knowledge of our own reality is being taken seriously. It is not somebody from outside, but in effect, us telling ourselves. Keith (1996) reminds other disabled women that "it is essential to enter into dialogue...and not allow ourselves to be isolated from the people who can help us to interpret and analyse our world" (1996: 88).

Second, there tends to be greater trust from disabled women participating in research for another disabled woman as a researcher. Most disabled women, have experience of intrusive invasive interactions and questions that strip privacy, dignity and emotional equilibrium. Keith calls such interactions as "encounters with strangers" (ibid: 69). Disabled women tend to expect that another disabled woman, somebody who knows about the invasive questions will not do such things themselves. As disabled women begin to record research work among their own communities they affirm this perception. For example, Varian (1998) conducted research among other disabled women. She comments that responses to her questions were given in very considerable detail because they were giving information to another disabled woman (1988, personal communication).

4. METHODS USED

In the previous sections I have moved from an overview of the components of methodology, and discussion of ethical issues to a consideration of research methods in relation to appropriate practice. I have done so in some detail in order to show linkages between theory, methods and research relations of power. I

argue that the model of this research and its theoretical underpinnings are both significant to disabled women, and require sufficient attention to the various strands of the project. The following features represent a translation of the discussion into concrete terms.

Consultation

In the three or four years preceding the research I undertook informal consultation within the community of women with disabilities. In a generalised networking process, I first raised the issue of recording stories of disabled women. The women I talked with responded positively as did the other disabled women with whom they talked.

I then crystallised my thoughts, and in a similar way, presented a more specific project to record oral histories for older disabled women, with a particular focus on work, and to be undertaken by me. I discussed a partnership approach to the project I also requested suggestions of women who might be interviewed. Again the response was very positive. Disabled women thought that the project was focussed correctly, supported the approach, suggested names, and offered practical support.

Finding Participants

The issue was not to find enough participants, but to limit the numbers of participants. I have noted that consultation received enthusiastic support, and the list of potential interviewees, both known to me, or to other disabled women was over twenty. There were, however, a number of limitations, and I needed to be clear on those to the women who wished to participate.

First, the interviews were of older women with disabilities: I chose to talk with women over 60 years. I have indicated earlier that there is almost no record of the lives of women with disabilities in Aotearoa/New Zealand. To build an archive, it is

sensible practice to begin with the experiences of the older members of a community, before their stories are unavailable, and the times in which they have lived become a once removed' memory. Women over 60 have lived through two world wars, various epidemics, and at least one economic depression. They have experienced many years of societal change, but much less change in relation to social attitudes. Their narratives are therefore set within both change and stasis.

Second, I needed to ensure that the immediate research project suited the needs of a masters thesis, so considerations of time for interviewing and for the project overall were significant. That is, the project needed to be of realistic size. In an oral history interview, Fyfe & Manson (1995) indicate that each hour of taped interview can take up to 15 hours to process, so the time commitment in using this approach is substantial. Supporting resources, including travel and equipment needed to be available, so the project had to take account of such practicalities.

Third was the issue of representing diversity. Women with disabilities cover a diverse range. This is in terms of their geographical location, the disability group they fall into[57], and how the disability came to exist[58]. For this research project. I chose to concentrate on particular segments of the community: women with physical, sensory or neurological disabilities. The gaps in comprehensive coverage of a range of disabilities are evident, but the project could not aim for comprehensive coverage. It is my expectation that there will be further work within the community of disabled women, to more adequately record its diversity.

Given the above considerations I obtained agreement to interview seven disabled women over 60 years of age, living between the mid North Island and the mid South Island. Most were women who I already knew, and who had already signified interest in the project. They came from a range of sensory, neurological

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[57] The generally accepted groupings are physical, sensory, age-related, neurological, intellectual, and psychiatric.
[58] A disability may have been present since birth, or acquired through illness or an accident

or physical disabilities, and there was a range of ways in which disability occurred. Some were disabled from birth, some in childhood, others later in adulthood. Disabilities came about through illness or through injury.

In two instances women I approached chose not to be interviewed. One had too many other commitments at that time, while the other was concerned that her speech impediment would present too many difficulties for all concerned.

Partnerships, Accountabilities And Ethical Standards

Accountability is seen at a number of different levels. I regard my ultimate accountability in both a practical and moral sense to the community of disabled women in Aotearoa/New Zealand, since they ultimately are the bearers of the information about the lives of disabled women, and because I have undertaken to begin an oral history archive for disabled women in Aotearoa/New Zealand through a process of consultation.

At a more immediate level I am accountable to the disabled women with whom I have worked on this research project, to use the information in the manner that we have agreed. I further owe professional accountability to maintain ethical standards of research work to the School of Policy Studies and Social Work at Massey University, and to the Massey University Human Ethics Committee. In addition, I have worked within the ethical standards set by the National Oral History Association of New Zealand.

The information form, reproduced in the appendices, represented the first stage of the partnership process that I had foreshadowed at the earlier consultative stage. I used the meeting or telephone conversation to discuss the availability of data, and how I would solicit participants' feedback. I obtained written and informed consent for the use of each woman's name. This, and the reasons for it had been discussed at the earliest stages, and was again discussed when consent for

information use and storage was obtained. It was a specific item on the consent form. Disabled women had the option of using a name of their choice in the thesis, and one of the women chose this option.

In the second section I have referred to the two-stage consent process which I adopted. That process made a partnership process more manifest, since it was a serious move in power sharing. It symbolised that the participation of each disabled woman in the project was not taken for granted.

Reference Group

There is an additional formalised accountability loop in this project. I drew together a reference group of disabled women to support me during the project. As disabled women who also had a variety of skills, they provided me with non-academic guidance and disability expertise against which ideas could be tested. They did not have any access to the interview tapes or transcripts. In addition they stood in the position of advocates for the interests of disabled women as a community.

Question areas and interviews

My question areas constituted a basis for discussion, since we expected that each interview partner would interpret the question and respond in their own individual way. The following topics were addressed.
- Family and childhood
- Significant or formative events
- Education
- Work, in the broadest sense of the word, both paid and unpaid , and including caring or parenting
- Being disabled, female and older: the respective and cumulative effect of these different identities and at different times
- Social and political context: events and attitudes of society, particularly towards disability. The impact of those attitudes

The question areas are intertwined. The first three of these topic areas are usually addressed in oral history methods (see for example Thompson, 1988, Fyfe and Manson, 1977). They are related to any or all of the other topic areas.

The seven disabled women with whom I completed interviews were Karen, Grace, Dianna, Sophia, Ann, Olive and Verona. Interviews lasted between 1.5 and 4.5 hours in total, and were guided by the response each woman chose to make. In the initial information sharing session, we had discussed an estimated duration for an interview of two hours, but I indicated we would talk for 'just the length of time it took'.

Interviews were arranged to take place wherever the disabled women chose, at a time that was mutually agreed. For example, I made five separate visits to Sophia in order to complete three hours of taped interview. Certain limits of the time an interview would take place were negotiated, as I do not drive outside of town at night. Other interviews were fitted around the demands of external routines: for example Olive's hospital routines. For all of the women, the venues of choice were their own homes. Both in timing and in venue, I sought to maximise the choices.

From Methods to Analysis

Implicit in the telling of the narratives is the process of drawing themes from the information, and pointing to the ways in which the themes converge and separate. I use a process of interrogating the texts, to determine the themes. Since topic areas rather than set questions are used this analytical process is consistent with the methods.

Themes emerge in three interconnected clusters. In the first cluster are invisibility, then attitudes towards disability, both as it is internally experienced and externally seen. Following from these two themes are expectations and the consequences of the attitudes. The themes are more interconnected in reality than the headings

might imply, and the interconnections, particularly in the way they relate to work are also pointed out.

In the second cluster of themes is the way disability, female, age, work are seen, and how they relate to, or diverge from one another. The third cluster of themes is, in effect, a summary of the two previous clusters. It is about living a whole life, and about a sense of identity.

Identification of the themes emerging from the content not only brings some order to the large amount of information but also it provides a process of reflection on the content. However, the material laid out in this chapter has indicated that content is not the only 'product' of the interviews. The following section addresses the additional process aspects.

5. REFLECTIONS ON THE INTERVIEWS

The final section comprises a reflection on some of the process issues which arose during the interviews, and how the issues illustrate methodology, ethics, or contradictions. I have drawn from the process diary which I kept, or other notes made to myself during interviews. The 'feeling tone' (Terkel, 1984) which has contributed to this section derived substantially from issues of process. It was also reflected in the tapes, while the written tape transcripts ensured my memory of the words used could be verified.

In conventional analysis of the data, the focus is principally on the content of a piece of research: the story itself, and the sequence of events. Chanfrault-Duchet (1991) has written that the content dimension of a narrative characteristically "encompasses not only the temporal and causal organisation of facts...but also value judgements....[It] represents a meaning system complete unto itself" (1991:77).

But content is only one aspect of an oral history interview. Chanfrault-Duchet (ibid) identifies two further aspects. First, the narrative deals with the relationship between the self and the social context. Second, narratives that come from, or are about marginalised groups often deal with complexities allied to this self-social content relationship. They can carry collective representations, or symbols of group experience. The disabled women I interviewed talked about the stereotypes they knew were held about them: for example that they should not marry, or have sexual relationships. They nevertheless took pleasure, in various ways, in ignoring the imposed image of disability and sexuality, substituting their own group experience: 'I can if I want to'.

Chanfrault-Duchet believes that when the material in the narratives is displayed in a manner that does not take account of these different features, the richness of the material will be missed. Frisch (1990) extends this point by listing some of the questions that using an oral history method will raise, and which might be missed. The questions, he says, include:

> What is the relation between interviewer and subject in the generating of such histories-who is responsible for them, and where is interpretive authority located? How are we to understand the interpretations that are essentially collaboratively produced in an interview, whether the relationship is one of cooperation or tension? How can this collaboration be represented? (1990: xx)

I have drawn from the above insights, particularly Frisch's questions, to shape the remainder of this section.

Being on tape: 'Performance'

I begin with an acknowledgment that putting a story on tape can be an overwhelming exercise for both interviewer and interviewee. The interviewer is always conscious that this is a very public exercise. The unedited original of the

tape, with all of its deviations from perfection is archived and is available to any other bona fide researcher. Unlike the written extracts or other forms of research reports, tapes cannot be tidied or re-packaged. The wish to do 'better' was always present. It also acted as a useful self-monitoring device: a spur to ask 'better' questions next time.

Interviewees likewise often doubt their competence to say anything or say it well. When they hear tapes of their interviews, they are often appalled by the repetitions, hesitations and deviations in their patterns of speech. They are also concerned with how they said something, or with the impact their material might have on others. Although the matters might have been discussed often among family members, the existence of a tape seemed to somehow be more final, and with greater potential for damage.

Most participants in an interview share some of these concerns, to varying extents. The point here is how the 'performance' anxieties of both parties are a particular factor to this research. It should not be forgotten that the stories I have collected here have come out of a silence, from a marginalised group. There are infrequent occasions for disabled women to reflect, on tape, about aspects of identity, and about how they themselves see their lives as disabled women. Talking on to tape about disability can thus constitute an act of defiance, and can raise huge performance anxieties. I discussed an interview with one woman who has a speech impediment. She chose not to record because she had been so used to being 'translated' all her life, and had come to believe that her own voice was not good enough: that people would not listen, that it would be impossible to transcribe. But she did not intend for her story to be filtered through another's translation. Whether or not to talk on to tape raised issues of accountability and authority.

An issue allied to performance is the effect of telling stories. Bhabha (1994) writes of the subversive potential of "in between" (1994:190) identities. He sees such identities as constituting a place from which society's dominant images can be questioned. When the realities that are actually lived and articulated by them are set alongside the images that are dominant, scepticism grows. It may well occur within those marginalised people themselves. So the women, who may have accepted, to varying extents, what society's images have to say, re-evaluate the 'given images. A socially constructed reality is, in Tierney's words, "constantly undergoing reinterpretation" (1993, 129).

Telling a story provides a forum to re-evaluate or question what has occurred, and to question. For example, Sophia describes her hidden disability of psoriasis in terms of revulsion, shame and poor self image. Later, she found cause to re-evaluate what psoriasis, and disability in general means. She formed an alternative concept of disability, and the telling gave her the chance to reconfirm her decision.

Interviewer-Interviewee: A Shared Author-ity?

> Who, really is the author of an oral history, whether this be a single interview, or an edited book-length narrative? Is it the historian posing questions and editing results, or the 'subject' whose words are the heart of the consequent text? (Frisch, 1990: xx)

When the research was designed, processes to ensure that there was equal participation were built in. For instance there is joint copyright on the tapes, a two-stage consent form kept control of taping with the interviewee, and there have been ongoing feedback-monitoring loops regarding the stories, particularly in transcript form. But in the process of an interview, equal participation is fluid. The "rules" of this contact are neither explicit nor even well formulated. To negotiate shared author-ity throughout the interview is necessary. Thus I constantly checked

for clarity with the woman I was interviewing. The following examples show this process.

Grace described how she perceived any male or female differences in access of blind people to equipment. Anne talked about common social perceptions of disabled women. Verona described comparative rates of pay at one stage of her paid work. I would question "so was that X?" or "do you mean Y?" or propose "sounds like Z, is it?". Women would respond to this en-route checking with acceptance-"Yes, yes, that's it exactly" or rejection and reformulation-"well, I don't know" The net effect in the interviews is one of constant interaction, of sharing responsibility for the production of a story.

A shared author-ity has particular relevance because the interviewer is also a disabled woman. The temptation of an insider is to feel you know what an interviewee is saying, or can frame it so much better, or can interpret its significance 'properly'. Further the position of interviewer means it is easy to impose on the story. Hooks (1990) describes such a process of imposition:

> No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it becomes mine, my own. Re-writing you, I write myself anew. I am still author, authority.(1990:152, emphasis added)

The process of constantly checking out en-route does not remove the interviewer, but frames the interviews so there is sharing the goal of a accurate expression of the point at issue.

Growing the Stories: Interviewer and Interviewee.

Who is responsible for generating the stories, and where is interpretive authority located?....How can a collaboration to produce a representation in

an oral history be represented, and how is it usually mystified and obscured, and to what effect? (Frisch, 1990: xx)

I have written elsewhere (Wicks, 1996-7) how disabled women have been disadvantaged by research from which their voices, wisdom and expertise are absent. It is of concern to disabled women that the record of other people speaking for us and interpreting who we are and how we live is poor. In research, where others speak for disabled women, meanings can become different as the words are interpreted via some other's framework. A self-defined sense of identity becomes elusive. The net effect of that was encapsulated in a 1994 conference, when an unknown Pacific Islands woman said "we lose our humanity when others take it upon themselves to tell our stories". These are important considerations underlying a woman's decision to agree to an interview.

It was appropriate for the interviewer to be a disabled woman. It was also significant because, on an implicit level, it signalled that the community of disabled women and their stories were to be taken seriously. In terms of generating stories the implied respect meant, for a number of the women, a choice to talk at a more candid level. To some women, the choice was implicit in their actions. When Sophia chose to talk to me, she was very unwell. Pain and exhaustion were ever present. She chose to talk to another disabled woman because her story, including her record of the beginnings of DPA needed to be known by other disabled people, and she knew the effort involved for the disabled interviewer.

Sophia was explicit about the significance of talking to, sharing with another disabled woman:

It's the sharing, rather than the saying and doing that's important, I think...It's there, and that's support you get that you don't get from an able-bodied person because they don't know what you're going through....You've got something in common, which you cannot share with able bodied people.

Sophia saw an equal collaboration as a given in the research project We were together responsible for the emergence of the stories.

Other disabled women told stories from their lives with an implicit belief that their significance would not be distorted or minimised by a non-disabled frame of reference; they seemed to feel assured that an 'insider' would respect the story's significance. Anne told of unpalatable attitudes towards sexuality or marriage for disabled people, then of a supervisor who made sexual interpretations on her needs for access. Grace described her experience of redundancy and how the employer informed all sorts of 'support' people before talking to her, in order to 'manage' her supposed reaction. On Olive's shopping expedition with a male companion, the assistant spoke to the companion when Olive was inquiring about the item.

It might be objected that such incidents could be told to any interviewer, whether they are disabled or non-disabled; that hearing such a story signifies little about the process. I acknowledge that stories of considerable significance are told to 'outsiders' and I am sure there are many sound non-disabled women of undoubted probity.

However, I found a repeated pattern of stories told about stereotyping, discrimination or other concerns for disabled women. Episodes of discrimination involving one group to be reinterpreted, even minimised by non-insiders. Women with disabilities are aware that the common reframing of such episodes puts them in terms of individual experience, or some deficit- in effect obscuring the meaning of the episode- but that is much less likely with an appropriate listener. In effect, the disabled women 'voted with their stories' for the presence of another disabled woman as that appropriate listener. That is, they often chose to tell particular stories because of the appropriateness of the interviewer.

Taping Ourselves Seriously

In oral histories, a high value is placed on the achievement of technical standards. Fyfe and Manson say "a poorly recorded interview will result in a sound document that may be unreliable" (1994, 1). Equipment, location and recording techniques are thus given thorough attention. If tapes are to form a permanent record and be stored in archival settings, it is of little use to produce an interview tape that is largely inaudible.

Lists of technicalities to remember when interviewing spell out ideal circumstances for an interview: a quiet room, with neither personal interruptions nor mechanical noises in the room. The interviewer performs technical routines with her or his equipment, and electrical outlets or fresh batteries have preeminent importance. External noises should disappear quickly, and the interviewee never fiddles with the microphone cord, a pen or their clothing.

While technical quality is almost completely the responsibility of the interviewer, I argue that the recording of disabled women may well necessitate further considerations additional to the technical baseline of competent recording technique. In my interviews, this meant additional 'noises' which constituted auditory 'markers' of circumstances. They confirm or affirm the extent to which physical circumstances are part of each woman's life, and I argue that their presence is extremely valuable, since they testify that ideal circumstances and reality can differ greatly.

For example, the interviews with Sophia were recorded in a small room very close to the main highway, and the main railway line in the North Island. Movement to another location was impossible. The noise of heavy traffic and frequent long trains cannot be excluded from the recording, but I made no attempt to exclude the noise was made. Here, background noises constitute background testimony to Sophia's situation of immobility and lack of options.

In the interview with Grace, the phone rings regularly. Having audible and orienting signals reminding of the world's presence is an important feature of a blind woman's life. It is significant to her in the same way that visual signals are to a deaf woman, as it can constitute a matter of safety. Here too no exclusion has been attempted. It signifies what importance communication has for a woman with a sensory disability.

Olive's interview takes place in the hospital room she lives in. It is her home, her own private space. But it is also part of a hospital ward, and has all the sounds usual to a hospital ward. So buzzers ring, trolleys clatter, and people converse in the corridor outside, and nurses are liable to make unscheduled entries. Nothing is a deliberate attempt to be awkward: it's just the way hospitals are. To live in such an environment is to exercise minimal control over it. As in Sophia's interview, the noises of her everyday life are present on the tape, testimony to her limited choices.

In choosing to have such noises on tape at the cost of theoretical technical perfection I have conveyed an implicit message: it was an unspoken acknowledgment of a disabled woman's reality, and conveyed respect for that reality. That, in turn, contributed 'room' in which the stories could be generated.

This chapter has moved from a discussion of broader scale considerations in methodology, and ethical issues to the more concretised matters of methods. My description of the application of the methods of choice to this project has served to illuminate my reflections on the use of the methods.

Throughout the chapter the presence of power relations, has been evident, as has been my response to this in through a relationship of partnership in a research project. The processes I use are consistent. with the values I hold, and I assert

that the outcome of these processes of partnership has benefited the community of women with disabilities. In discussing the value of partnership within research, Lincoln (1993) comments:

> Such [dialogic] processes can be taught, but they are best and most efficiently taught via modelling ...with dialogue, dialectic and criticism will collaborators in research come to a new understanding...about the circumstances of their life. (1993: 42-3)

The following section will trace the life stories of the seven women who were interviewed in detail but also in summary. Even in the shortest interview time of 1.5 hours, there is a wealth of detail that could not be reproduced in these summaries. But the impact of events and attitudes is evident.

PART TWO

INTRODUCTION TO THE STORIES

In the chapter on methodology in the first part of the thesis, I discussed the way these stories could be told through an oral history method. In this second part, I present the seven separate life stories of each of the disabled women I interviewed.

The narratives are of varying length, and reflect the length of time for which each woman chose to talk. The order in which the narratives are arranged has no significance: I have made a random choice of sequence.

The narratives here are largely drawn from the words and phrasing used in the interviews by each disabled woman. I have aimed to convey faithfully the story which I was told, but there is an additional dimension of keeping faith. It is conveying the way in which the stories were told, a sense of the disabled woman's essence. Terkel (1984) calls this dimension "the feeling tone" (cited in Lincoln, 1993).

I have added my words to the narratives in Part Two sparingly: where contextual material or explanation is necessary for purposes of clarity. In Part Three, which follows, I will resume my input as I analyse and discuss the themes arising from the narratives.

GRACE WHEELER

To talk with Grace is to have conversation punctuated by the signs of a busy, sociable life. The phone rings constantly, the mail box is full, and she has a stream of appointments. Her guide dog Zoe is also sociable, and usually induces visitors to take part in a spot of ball throwing. To take part fully in social activities and conversation has always been part of Grace's life and she has developed her readiness to engage with others into advocacy skills for other blind people. She is very happy with many people and many things.

In the large working class family that Grace Rogers was born into in 1932, she was the oldest of the 8 children of her father's second wife, who was 24 years younger than her husband. He had already had 8 children by his first wife, and as these children of the first family grew and moved away from her father's small Mount Wellington farm, the second family expanded.

Her father had settled on the surname Rogers after beginning with Baker or Boyd, from which he was, for an intermediate period, known as. These name changes were occasioned by brushes with the law over liquor and minor firearms offences; a testament to a tempestuous period in young adulthood. By the time Grace was a child, all that remained tempestuous was his thatch of white hair, which usually stood up on end.

Grace's remembers Mount Wellington of the 1930s as a very rural area. The community into which Grace was born was close knit and shared a number of large rural tasks. The haymaking, for instance began when all the neighbours turned up to help the person who owned the cutting and bailing equipment. Following that, "they would go out round and do all the paddocks. Everybody would turn out to help everyone else" (8)

The children of the area were likewise communal in their play; Grace's brothers would contact the next door neighbour's children by "climbing on the cow shed roof, and in a way make a sort of whistle type noise by blowing through your hands" (3): a signal for any child to meet in the hay for games inside the empty water tanks there.

With so many to provide for, and a depression under way, her father found employment as a freezing worker at Westfield freezing works, while her mother ran the farm they owned. For her mother with many children, and a farm to run, life was always full of work. She had to take small children with her while she performed farm tasks such as collecting eggs from the hens, or digging a new pit for the privy. In the weekends, Grace's father laboured over farm tasks, and maintained a huge vegetable garden. Both parents rose each morning around 4 am, so it is little surprise that they were usually asleep by 8.30 pm.

Hard work was a theme in family life, and all contributed their share. The children all shared responsibilities for maintaining the household from an early age. Older siblings would ensure that the younger ones were dressed, breakfasted and ready for school. In a rota of tasks, both daily and weekly, they kept the household ticking over.

There was a strong sense of shared family life, for example a family sing-song each night. The sound of all the children lustily adding their voices "must have sounded really bad" (4), but was greatly enjoyed by all. It nurtured a love of singing in family members, who subsequently performed in choirs or singing groups.

Grace's loss of vision came in two periods, separated by 31 years. The first injury to her right eye happened in 1936, and was the consequence of a fall at play. At first the injury seemed minor, but ultimately resulted in a stay in Auckland Hospital,

and the attentions of various specialists. Grace did not like hospital, and was a bad patient. But she "felt quite good about being noticed" (6) as a result of a small naughtiness. She left wearing glasses, as there had been some damage.

The second injury to her right eye was in 1939. It too happened in an accident at play, and also brought a period of hospitalisation. The result was a loss of sight in the left eye, but this was not felt to be a major impediment: there were " a great many people who get around with one eye" (6). However, doctors at the hospital were concerned to conserve Grace's remaining vision. They thought school attendance would involve too much boisterous contact, and persuaded her mother to keep her away from Panmure Primary School. When all the other children went to school, she stayed home with a very busy mother and younger siblings.

Her mother had neither the time nor the training to provide any home schooling. Her 'solution' to the issue of what Grace would do was to have her sit on the front step and nurse some expensive china dolls. Grace's mother "thought it was quite good" (7), but Grace "wasn't keen on it at all". She was lonely, bored and of an active disposition. Eventually, she found the open-ended days with which she was faced offered her the opportunity to get up to mischief. She would, for example, raid orchards, and dip her spoils into the cream cans which awaited delivery outside farm gates, before eating them. Or she would "borrow" push bikes from neighbouring properties and abandon them elsewhere. Gates were left open, and stock wandered to inconvenient places.

Her mother would not, at first, believe that "her Gracie" would do such things. She was, after all such a small and quiet child. But the complaints continued, and when an ultra-respectable neighbour accused Grace of writing 'swear words' on one of her doors in chalk, her mother believed the accusation. As a result, Grace was hastily returned to school after a year long absence.

By the time of the second eye injury, free universal health care had been introduced. Its availability may have made her second period in hospital less of a financial burden for her parents. With a large family to maintain, money for health care may well have been a concern to her parents. But they did not discuss any issues or worries in front of the children. Her mother's attitude was that any such matters were a private concern. Her usual response to a difference of opinion, "well that's all right, we'll speak about it later" (18) typifies this approach. Matters of financial hardship appear to have made little impact in Grace's young memories, and war years have similarly left little trace.

When Grace was 16 the family moved to a more urban location in Penrose. The new house possessed a compelling attraction for the whole family: a flush toilet on the end of the verandah. When they first moved in "we all went and pulled the chain, and we pulled the chain, and pulled the chain some more because it was quite exciting." (15).

In Penrose, the young people of the family formed part of a group of local youth who took part in many leisure activities together. Grace's favourite activity was dancing and going to the Saturday night dance was a weekends routine. Provided that household tasks which were allotted on a rotational basis were done, her parents encouraged enjoyment and hospitality. It was usual for numbers from the group which went to the dance to stay overnight at the family house. Grace's mother, long used to dealing with large numbers of young people, was comfortable with the temporary additions to the family.

All family members participated in the tasks needed to run the household. Grace's mother believed it was necessary for her sons and daughters alike to be able to look after themselves independently, and undertake all the ordinary household tasks. So all sons and daughters performed all the tasks equally, except for

washing dishes. Grace's father kept this task to females only, and the daughters greatly resented the situation.

Equal expectations were likewise held about education. Reading and writing were highly valued as it was seen to enable a person to take advantage of opportunities or of knowledge gained. The family was large, although "we were not poor, but we were not rich" (16). Nevertheless, money was used to ensure that books, usually given as presents, were available to the children. Grace loved to read, and used books as an adjunct to household tasks. She would dust under beds with a book in hand, and become absorbed in the story, until her mother's footsteps led her hastily to resume her activity. She also read under the blankets by torchlight.

However, academic learning was not overly emphasised. Although Grace adored reading, she also enjoyed the more practical aspects of her formal schooling. When she reached school leaving age (15), she took up the commercial subjects she had studied, and began working in an office (Farmers). But she soon found she "couldn't bear the sitting in one place" (18), and so she moved into the more practical and active areas of factory work where there were a variety of tasks. From there, she moved to working as a nurse aid-again activity and variety were desirable features of the job.

A further desirable aspect of such work was the opportunity it gave for contact with many people. As part of a large family Grace enjoyed constant social interchange, and the experience of many differing opinions. The family's approach was ordered and tolerant. Differences were respected so that:

> I can have words with somebody, a difference of opinion, and even if I'm in a meeting, even today, I always hope that if I disagree with you in that situation, and we have differing opinions, that our opinions are respected, and that we can get up and walk out of that meeting, and go on with

something else that we're interested in, without having any bias or ill feeling towards each other. (17)

To Grace, rows and sulking have always represented wasted energy; the key issue was respect for differences. This is a principle that Grace has found to be "very very important" (18) throughout her life, and to which she has adhered over time.

Respecting differences was also reflected in relation to disability. A neighbour's daughter had difficulties with mobility and coordination, and did not go to school. Much of her time was spent in getting to, and visiting at houses nearby. Grace recalls that this young woman's "ability to walk and talk was different, but we just treated her as an average person It wasn't even thought about as being a disability. We never said 'she's got a disability, she's got something wrong with her' or any of those sorts of things" (18).

At 19, she met her husband through mutual friends. Agreeing to marry him was a somewhat casual event in a busy and sociable life: it happened in a rapid and offhand manner, with little time spent on reflection. Two to three months, interspersed with his absences for his employment as a merchant sailor and a small number of outings after they first met, she obtained parental permission for an under age marriage license. Grace still finds the whole sequence somewhat baffling

It was quite queer really. I shouldn't be saying all this now, but you know, you sort of think 'oh my goodness'....I don't know if it was a shock, but just 'oh goodness me, what have you done?'. (21)

The couple moved to Wellington, and her husband continued his work as a merchant seaman, then moving to the Post Office. Grace worked for several years as a nurse aid, but in her late twenties her eyesight again caused problems, with blurred vision in the left eye. It became increasingly difficult for her to work as a

nurse aid, and incidents such as using fly spray rather than deodorant spray at work convinced Grace that she needed employment where reading was not such a vital aspect. A messenger's job with New Zealand Railways offered the variety, activity and people contact that she enjoyed.

However the visual difficulties in the left eye continued and got worse. By 1964, pain in both eyes added to blurred vision in the left, and she again had visits to hospital ophthalmologists. As a result of their examinations, they removed her (blind) right eye on St Patrick's day 1964. This had the unexpected effect of relieving the pain in her left eye.

It had been planned that Grace would be fitted with an artificial eye, but she developed an allergic reaction and fitting was not possible. Thereafter Grace used a black eye patch and found it brought an unexpected, if unspoken comradeship, with three other people in Wellington who also wore black eye patches.

The eye patch was an unexpectedly useful adjunct to the fund-raising activities that Grace took part in. Dressed as a pirate, complete with eyepatch, she 'caught' travellers at Wellington railway station and asked them to contribute to an annual appeal for a blind children's charity. She wondered if the travellers considered her or her fellow collectors-large watersiders dressed as fairies- to be a lesser evil.

Vision in her left eye continued to diminish though, and various specialists were unable to pinpoint the cause, or to arrest the loss. There were repeated attempts at surgery to the retina, which characteristically had some effect for a while, before the problem recurred. By 1966 "it only lasted seven or eight days, and I'd loose it again" (24) In June she was aware that it was again retreating and had gone to hospital. Her experience at that point of "watching myself going blind, because the eye, the retina was coming across" (25) was very upsetting. After this episode, no

further surgery was possible, and ophthalmologists told her to adjust to a complete loss of vision.

This was not easy. Initially she told herself that something would happen and she would somehow get her sight back. But when the full impact of her situation hit her six months later, she had a "nervous breakdown". She spent much of the summer in bed, with her nerves feeling stretched to breaking point.

Her company and solace during the summer of 1966-67 came from listening to one particular cricket commentator on the radio. During the 'breakdown' period of around 3 months, the experience of hallucinations and feelings of unbearable nervous tension was soothed by his voice. Her general practitioner was sure that she could and would return from this uncomfortable state and she found support in his assurance.

The impact of her situation was added to by the way in which her husband and his family dealt with the issue: they found it hard to adapt to the new circumstances. Her husband attempted to do everything for her but in all that he did he was so "concerned that he'd do something wrong that he was concentrating on that more than helping me...I became the best ballet dancer in the world when he was trying to help me up and down kerbs" (30). His attempts to do everything for her were founded on a belief that her disability represented something everlastingly dreadful that could not ever be right, and it distressed him greatly. He would exclaim to others, in her presence "I just know I couldn't stand it! If it were me, I'd be down there, throwing myself into the sea. I just can't understand how she can put up with it!" (30)

His brother and his brother's wife were no more sensitive. When she would turn to face her brother-in-law as he spoke, he would say he was unable to stand it, because she couldn't see. His wife was equally insensitive, and insisted to Grace

"ooh, don't sit in front of me with the [dark] glasses off" (30). Grace found coping with their problems over her disability tiresome.

Her husband and his relatives clearly regarded disability as a fearsome painful thing, and a personal tragedy. That state of suffering provided her, or any disabled person with no quality of life: "you know he could never understand how I could get up and walk, and do the things I did.... And it's not only me. He's referring to anybody that it happens to" (31). Such negative attitudes and behaviours towards her disability would be repeated occurrences in Grace's life.

Just as the 'breakdown' was sudden, so was the return to her more usual pursuits. she got up and began to take up the tasks of everyday living, learning to perform them in new ways. Acquaintances later told one another that "once Grace Wheeler got on her feet you couldn't stop her-she was poking her nose into everything" (32).

Grace had maintained her connection with the Royal New Zealand Foundation for the Blind (RNZFB), first established in her teenage years. As her remaining eyesight was going, her ophthalmologist's urgings led her to join the RNZFB. Now she began to use more of its services as a blind consumer. She learned to make her way around again, had already begun to learn braille, and play blind bowls. She acquired her first guide dog Heidi. It was all very different from her existence with partial sight.

New Zealand Railways (NZR) had kept Grace's position open for her while her eyesight needed treatment. But it became apparent to her that she would not be able to continue in that position and she left. For the next four years, Grace undertook a wide variety of unpaid work connected with RNZFB activities.

In 1971, a position in a mechanical assembly plant became available, and Grace and her husband shifted to the Hutt Valley where and she worked in the stores division. It was here that attitudes and behaviours about what disabled people could not do became apparent to her

Grace had already become aware of such prejudices, and had made some effort to avoid their consequences. While she was working at NZR and her sight was deteriorating, she made strenuous efforts to keep this from other people on the staff, because:

> You wanted to carry on working, and you think in the back of your mind you might loose your job. All sorts of things or people might not allow you to do the things you are doing because of your loss, well whatever's happening to you (36).

Now, in her new job, Grace began to find out how to perform her job in ways that fitted her blindness. As she became sure, she extended her range of tasks, locating and counting items, assembling small cartons, or making up orders.

This brought a reaction: incredulous managers came in groups to watch as she assembled cartons, asking one another "how does she do it?" (39). Grace's capabilities did not fit with the prejudices of a supervisor who declared "There isn't a job in this department that a blind person can do". (39). She did 'do', and when she left the plant, she dealt emphatically with this prejudice to the individual concerned. She told him that his ongoing disbelief- he still did not know "how you can do it"-was the problem, as "all you had to know was that I could do it" (41)

Other workers and management gradually came to terms with her presence and the way she performed tasks and this acceptance was complemented by her abilities to speak out and advocate for others within the trade union. But Grace was always aware of a pressure to perform her work to a higher standard because she was disabled: "I always felt I had to be really on the top all the time" (40).

When the plant closed, Grace moved to another manufacturing firm and was again performing assembly tasks on electrical items. In addition, she noted disability discrimination in another form: how workmates bossed and bullied an intellectually disabled man working there. The people doing this "just felt somehow it was their right to do it". She contrasts the pressures on the young man who everyone felt the "right to tell him" with her situation where "People became quite careful about what they said to me about my work, and that sort of thing, and the speed of it" (Both 43).

In 1987, after 6 years at this factory Grace, along with four other staff, was made redundant. This caused her great anger, because of the way it was approached. Before she was told, her employer had contacted the RNZFB to ask how they should talk to her about the situation of redundancy. Grace found this improper and patronising. She reprimanded the manager as "there was no difference in speaking to me as to any other person in the place. The situation concerned me and nobody else,...I was the one he should have spoken to all the way about it" (45). She lectured the manager about his behaviour, and finally told him that she was redundant. On walking out, she discovered he had detailed another staff member to wait outside the door to provide tea and sympathy. She did not appreciate the assumption that she would need 'special' treatment because she was disabled, and decided to retire from paid work, and returned to unpaid work.

Throughout her time in paid work, but particularly from the 1960s on, Grace encountered a number of other people with disabilities in employment of a similar, blue-collar, nature to hers. In contrast, most of the other disabled women in this project were in paid work of a more white collar nature, and their experiences of other disabled people in the workplace is sparse. Grace saw more disabled people because the work she was doing was the kind of work disabled people were more likely to obtain: blue collar or unskilled jobs.

Relations between Grace and her husband, which had become strained after she became blind, continued to be friendly, but he found it increasingly difficult to live in the same house as her. In 1975 he was transferred by his firm to Auckland, and he went alone. They then pursued separate paths, but remained married. Friendly contact, including regular visits, has continued since then; both still regard the marriage as very much intact.

Following her retirement, Grace turned her full attention to the many facets of unpaid work she took up after she became blind. The ability she had developed to speak out and advocate for herself and others ensured she found herself in roles of leadership. Grace has been a board member and sole consumer representative on the RNZFB board, and president for a number of groups such as the national guide dogs association.

This unpaid work has, for many years, existed alongside her paid work. Grace has long been involved with voluntary organisations, from assisting blind people with shopping as a teenager, to hospital visiting in her 60s. That these activities of unpaid work are just as important as is paid work is an unspoken value in her narrative. She describes all of the tasks she undertakes, paid and unpaid in even-handed terms that make it clear that it is, in her judgement, all work of value. Grace is very aware though, that the equal status she accords is not shared by most people: paid work is seen as more important. She points this out in discussing the different access to equipment that assists disabled people to perform work. She notes that disabled people undertaking unpaid work are unlikely to access government funding to purchase items such as optical scanners or hearing aids, which help people to read material, or participate in meetings. Such a situation is, she feels, "terribly unfair" (62).

While the unpaid work has largely focussed organisations for blind people, there has also been an involvement with wider disability interests. In 1983 Grace took part in the meeting which set up Disabled Persons Assembly (DPA)[59] in New Zealand. She strongly supported the new organisation, and became first president of the new branch of DPA set up in the Hutt Valley.

Grace has seen improvements to the position of disabled people over the last quarter-century, so that they are more in charge of their own lives, more "in the public eye" (60). Nevertheless she strongly supports human rights for disabled people because "We're not into a world yet where we can go without having those rights those human rights" (59). She still sees discrimination towards disabled people, such as she experienced at the mechanical assembly plant, arising from the attitudinal barriers of non-disabled perceptions of inability of disabled people. The change in attitudes has been "not, not a great deal" (60).

More significantly, she is made weary by a 'single miracle' approach where

> They'll say 'oh aren't you wonderful! You're able to do this and you're able to do that'. And when you say 'Well look, that is no different from what quite a lot of other people with disabilities do?' 'oh, is that so?'. It gives you the impression they think you're the only one, so they go to the next one, and treat them the same. (60)

Grace is irritated by this approach since it both over and underestimates what a disability means.

Over twenty-odd years in which Grace has been undertaking advocacy in blind and disabled sectors, she has watched a developing sense of disability, in which speaking out and assertiveness have been a feature (49). Her own development illustrates this change. From beginnings as a person who would be "shaking with worry about how I was going to cope when it came my time to speak" (48), Grace

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[59] DPA is now known as the Assembly of People with Disabilities

has become a person who speaks out readily when she judges that the situation requires it.

Grace has become aware of the impact of age as she herself ages. Although she feels fairly fit, and in reasonable energy, she has noticed that the existence of several different disabilities, including a loss of vision as an individual ages means it is "very very hard for people"(63). Further, she is aware that age has an additional impact on the perceptions others have of your capabilities, and comments, in relation to the roles she undertakes that age is a factor:

> People think 'ah, I notice she's a bit older, I wonder how long she's going to stay there' and your support goes down, not because you're any less able to do the job, but because you're older in people's eyes. (63)

Age has a differential impact for men and women she feels, so that more is expected of older women; they are expected to keep abreast of matters while men are able to adopt a less active, engaged position. This greater involvement for older women includes caring activities, but Grace's perception is that active involvement in caring has always been an expectation for women, but not for men. It is something she believes that blind women are well able to do: "keep up with the play, with the many things that they've been interested in" (65).

Postscript

At the end of 1997, Grace and husband Chris moved to Masterton to share a house again.

DIANNA GOSS

Spiritual conviction came to Dianna as a teenager, and it has remained a pervasive influence in her life. It meant that she saw, with great certainty, when openings about her work were the right ones for her. It meant also that living with a progressive disability was set in a sense of serenity: in the words of 12th century mystic Julian of Norwich, "All will be well"

The sense of control, of sureness about what is to be said pervades this interview. Dianna holds onto a great amount of reserve, so that what she chooses to say remains a 'surface' story, retaining privacy, and with the outline or summary available. She is imprecise about when events took place, and the picture given of many events is in broad brush strokes rather than in precise detail: as though the essence of the action, of what is most central to the story, as experienced by its protagonist, is highlighted. It is, however clear and bright.

The conversation is at a level of events: descriptions of what has happened, rather than thinking aloud about what the events might signify. Despite this orientation, there is a sense of serenity and honest interchange to the encounter.

As the only child of a career soldier, Dianna spent parts of her early life living in the different places to which her Australian-born father was posted. There was not enough money to pursue his wish to become a civil engineer, and he had begun a military career towards the end of World War One, attending officer training at Duntroon after the war ended. This officer-training was added to with a period spent at the English training establishment at Camberley when Dianna was a child. The war was almost over as he just got there "about the last six months or something...he didn't ever actually have to do any fighting" (1).

'Home base', to which the family returned after each posting was Days Bay in Wellington, and it was here that Diana was born in 1925. Although her New Plymouth born mother, who came from a family of 10 brothers and sisters, wanted more children, Dianna was the only child. Her birth was difficult and she was a Rhesus positive baby. With considerable regret her mother followed the doctors advice against bearing further children.

Being an only child did not mean loneliness though. Dianna spent a childhood with a number of friends, and had common patterns of sociability. As well as school friends, there were always other children living close by, both in Days Bay, and in the different locations of postings.

There were three major postings, with the spell in England at Camberley succeeded by a period in Australia, then to Napier, following the earthquake of 1934. There were other postings, of a more transitory nature, and Dianna has a sense of a childhood spent very much on the move. Despite this, schooling is recalled as pleasant and ordered. In Napier, a classmate who had been injured during the earthquake was treated protectively:

W   Did she get a hard time from the kids?

D   Oh no. I think we must have been quite a nice lot really. Everybody just didn't. (4)

Dianna has no other outstanding memories of schooltimes.

The depression of the 1930s made a strong impression, leaving Dianna with a lifelong habit of careful money management. While her father's employment was not at risk, he, in common with many other public servants, took cuts in pay:

we had to be very careful....I can remember when the pay cuts (sic) were going to come back, and he said he'd got a pay rise...they'd given him another shilling...because of that I've always been terribly careful about money. (4-5)

This was reinforced by the extra costs associated with her mother's illness. When Dianna was 10, her mother became ill with a kidney complaint, later identified as tuberculosis of the kidneys. The process of diagnosis involved doctors visits, hospital tests, laboratory analyses and specialist consultations. But free medical care through the state was not available until 1938, and so the strain on family finances from diagnosis and treatment was large. Dianna was very aware of what the presence or absence of money could mean.

Tuberculosis of the kidneys would diminish her mother's kidney function, resulting in a build-up of toxins in the body, tiredness, and some pain. But Dianna's memories of her mother during her prolonged illness are very positive. Throughout this period, Dianna remembers her mother as a cheerful and friendly person, who drew others to her. She was a person who "whenever she was in hospital, she was the one that the nurses used to come and talk to, and everybody enjoyed her" (26). Her mother died in 1946, when Dianna was 21.

The last "away" posting for the family was to Napier, which came just before the discovery of Dianna's mother's illness. Thereafter, her father remained at military headquarters. But he still went to World War Two, taking a role in the Pacific campaign.

It was during the war years that Dianna, at 16 began to take herself to the Anglican church at Karori, where they now lived. She had been introduced to Anglican forms of worship when she attended Chilton St James, at the beginning of her high school years, and while the family was living in the Hutt Valley. But she became religious of her own accord, as their family had not been regular churchgoers. It was the liturgy and ceremonial forms of Anglican worship that resonated with her sense of spirituality, indeed, for a period the spirituality was intense indeed: she thought of becoming a nun. While the intensity of spiritual

expression diminished, her sense of faith never did. She was ruefully aware that her family considered her behaviour extremely eccentric, although it was never a matter of discord, as relations with both parents remained open and loving. But her sense of vocation was not so overwhelming that she gave up all plans for tertiary studies.

Because "it never occurred to me that I wouldn't" (6), Dianna continued through to the 7th form, and then completed an MA at Victoria University by 1947. She saw the path to a degree as quite natural, and that she was one woman in many, as it was wartime, made the issue even more matter-of-fact. There were many more women than men at university, but though men were away at war, she noted that almost all lecturers were still men: "there was only one woman lecturer (6). That there were a considerable number of other women doing degrees was encouraging.

Her mother died in 1946, the year before her degree was completed. The eventual death was expected, and accepted with resignation. She had given Dianna an enduring legacy: a positive approach to living with disability. In her mother, Dianna saw a warm happy disposition that was not noticeably altered by her tuberculosis. Further, she saw others reacting positively to her mother. Such an example provided, in effect, a counter-image to any negative stereotype of disability:

> I hadn't thought of being disabled as being a shameful thing. Everybody enjoyed her, so nobody was sort of sorry for her. And I remember saying once 'oh well I'll be quite happy to have some disabling disease, but I don't want any pain'. It was, in a way, asking for trouble, wasn't it, because that's exactly what I got, and I don't have pain. So in a way, she has been quite an inspiration to me. (26)

When deciding a career, her first thoughts were to work in an orphanage, as she saw children from one at the parish church in Karori; "I thought they looked pretty

miserable, and I'd like to go and work there" (7), and was moved by their appearance of misery. She also considered teaching.

Although Dianna had teachers in school and in Bible Class whose example encouraged her to contribute in a public sphere, her expectations of what work women might do were consistent with general societal expectations. She reflects that "there are all sorts of things that women do now that you didn't consider. I never remember a [woman] dentist or lawyer, or a bank teller; they were all men. There were all sorts of things, but it just didn't occur to us that women might do [them]" (10).

Her desire to "work for the church in some way" (7) made the strongest call, and she became a parish assistant at an inner-city church. Its location meant its congregation included a number of people from other places-overseas seamen and students living in nearby hostels. And it meant she could continue to live at home with her father. Her initial 'try-out' period for the job was a year, but she stayed for ten.

The employment she entered was, in most instances, performed by women: men were either ordained as ministers, or they joined the church army. Parish assistants undertook Sunday School teaching and parishioner visits, and a variety of other tasks as they were required. Little training accompanied the position, as there seemed to be little consensus about what the job might include, or how one might acquire skills to perform it. So Dianna sought to supplement the gaps in an unsystematic approach, by doing any "training thing where they taught you how to do Sunday School teaching and things like that" (11). This included correspondence courses from St Johns [Anglican theological college in Auckland]. She remained keen to learn how she might perform her role effectively. Pay for any church employee, even ministers, was low, but parish assistants were on the lowest end of the scale.

In 1959, after 10 years in St Peter's parish, she undertook a locum as a hospital chaplain at Wellington Hospital. The experience convinced her that this was the direction she wanted to take in her church work. It also convinced her of the absolute necessity that she train for this role. When she began the locum she had little idea of what was necessary. She had "thought I had to say the right things to the family and all that sort of thing, and you'd learn to say the right things" (12). She also thought that "there must be a little formula about how to behave in these situations" (12) in a book somewhere. It was therefore very difficult for her when such a formula did not present itself and she "just felt inadequate" (12).

But during that locum year, Americans who trained others in pastoral care came to Aotearoa/NZ to talk about what was involved in pastoral care training. Their concept of pastoral care fitted with her requirements, and the visit was well timed. At the finish of her year's locum, she applied to go to Union Theological Seminary, was accepted, and in 1961 left to train at a theological college in New York State.

During the year in which she was finalising details for going to America, a medical examination found that Dianna had multiple sclerosis (MS). She had noticed little at this point, beyond a slight; clumsiness, particularly with fine movements, and greater difficulty with balance, especially in the dark, so the diagnosis was something of a surprise. It was also a mystery. Although she had some familiarity with medical matters, she had not heard of multiple sclerosis. Her lack of knowledge of the condition may well reflect a more generalised lack of knowledge about it.

Few effects were evident to her and those that were did not impose major difficulties to her work. She reflected on her fortune: "I wasn't a pianist or a waitress or a seamstress or anything. Except that I tended to get a bit tired" (20). That it did not prove to be a barrier meant that she was honest if people asked her

about the condition. But from that point on she would "always tend to ignore it....I preferred not to notice" (21) if others made adverse comment or behaved badly.

Her studies in America stimulated and stretched her, as she took on new and stimulating subjects where intense concentration was necessary. Of all the subjects for study though, it was the pastoral care course that she found to be most exciting. In it, she undertook a year long internship at a child psychiatric establishments. She learned the rudiments of counselling which had given her such concern in her internship. She remembers early sessions where her supervisor "said it sounded like an afternoon tea party" (15). But further practice gave greater ease. A further three years, from 1962-65 were spent in increasing her pastoral care skills and acquiring the elements of supervision. She completed placements at three hospitals, two of which were psychiatric establishments. She came out of her time feeling much more confident that the counselling she was doing was better work. She was very aware of "dealing with yourself, and seeing how much what you do colours what you're expecting of other people....you realise how much you influence what you do with other people" (16).

Dianna was quite certain that pastoral care in a psychiatric setting was where she wished to work. Towards the end of her time in America, she obtained a position at Porirua psychiatric hospital on her return, at the age of 42.

In 1967, Porirua was a large institution, with around 1700 people. Dianna found the contrast with the hospital she had last been at, in Kansas was huge. Numbers in Porirua were large, and treatment methods were rudimentary. She feels this situation was, in part due to a lack of money. But she also describes Porirua as always "the poor relation of the mental health setup, which is the poor relation of the whole thing" (18), which highlights how a general attitude was that mental health was a very little concern. She felt that Porirua had some good and

dedicated staff, but they, and the people in Porirua had to fit around a vast and impersonal system.

Despite the impediments, there were people for whom good outcomes were achieved in spite of unpromising circumstances. An example was when a young man who had been in a very bad accident came to Porirua. He had:

> Been sort of written off in a general hospital. But when he came to Porirua, one of the physios [physiotherapists] got onto him, and it was quite amazing. He was walking, and discharged, and very very active. And they'd thought there was no hope for him. Good things did happen. (25)

It was not easy to work in a situation where there seemed to be limited possibilities for change to the circumstances of those whom one is counselling or otherwise supporting. Dianna found it was not easy to deal with the spiritual needs of people who found themselves in Porirua because there was nowhere else for them to go. It was draining when "all you could do was agree with them that they were in a pretty lousy situation" (25).

Although after her retirement she felt she "really had been there too long" and had become "a bit blasé about things" (21), tiredness was the main trigger to her early retirement at 59. The tiredness, which mostly arose from her MS, was combined with increased problems with balance. Following retirement, further effects became apparent and gradually she came to use aids to mobility and coordination, such as a car with automatic transmission, a mobility parking sticker, and a walking stick. It was no longer possible to hold onto the thought that her condition was something of an inconvenience, which had been "my way of coping with it" (23). Increasingly she would see her image in the mirror and "I think good heavens could that little bent old lady be me?" (23). Even so, the image Dianna sees reflected of her actual appearance "doesn't fit with the image that I still hang onto of myself" (23).

That image has not included any particular idea of herself as disabled. She does not choose to refer to herself in this way, and disability remains a rather distant idea. From childhood, she retains only one memory of disability; a girl whose skull was injured in the Napier earthquake, and who was waiting to have the damage repaired. In adult life there is a similar absence of any distinct 'disabled' image. Only a large man who had one arm and appeared somewhere in the public life at the time of her young adulthood is remembered. The occupations Dianna has followed are likely to have given more contact than average between her and disabled people. She worked for many years in a very large psychiatric institution, and before that had extensive contact with hospitals and other institutions. Yet disability as an identity is still vaguely formed in her conversation.

There was no conscious decision to live a single life. Dianna had a range of friends, including some possible partners. She had the idea that she would marry around the age of thirty, but when this did not happen, she was not particularly distressed. Life continued to be full, and she did not find it necessary to be married to be content. Instead, she chose to live closely in the society of others. But she enjoying the sensation of sharing. Before she left for America, she and her father had shared a house to the enjoyment of both. She was later left money by her godmother and the house she now lives in came from this legacy. Now she does not live alone. Dianna likes to have someone else in the house and "I don't like having meals by myself" (27).

Sharing her house also has practical benefits. Dianna recognises she is no longer able to undertake some tasks such as gardening, and tasks involving fine coordination are more difficult. But she wishes to continue in her preferred lifestyle, enjoying the art, books and music that have been part of her life for many years.

This includes the range of unpaid work that she has undertaken since her retirement from Porirua Hospital. It includes English language tutoring, being part of the Whitirea Polytechnic's governing council, conducting oral examinations for St John's Theological College, and supervision for pastoral care workers from a range of denominations. She regards all of her activities, paid and unpaid as 'real' work. But there is a subtle sense of difference in paid and unpaid work, as when she remarks that unpaid work "was quite hard work" but "when it's fun, you don't think of it as work" (28). In her life is profound sense of fulfilment, and gratitude that this has been so.

KAREN BUTTERWORTH

Karen's creative streak is found in most of her siblings. To the heritage of her artist mother was added the intensity of questioning thought and articulate nature of her father. Karen's passion for using words has been lifelong, and she pursues creative expression in prose and poetry with a fire that has diminished little over time.

In the South Otago district of the Catlins, uniformity in all aspects of everyday life was expected. Women were dutiful mothers, men were good blokes, and both sexes were devout Presbyterians. Emotions or passions were frowned on; to Karen it seemed that "the Presbyterian upper and lower lips were both made of hardboard" (56)

Karen's mother had painted before her marriage, and explored literature. She married late in her twenties to a bush farmer and sawmiller who had rebelled against a narrow Presbyterianism, and enjoyed reading. He also had waited till he felt ready before marrying. Although they might both have had non-conventional souls, they both came from working class families and knew that family life and employment in a depression required a certain amount of conventionality. His Shetland forebears owned a farm, but he lost it early in the depression. Relief work saw him work as a rabbiter out of Papetowai. Karen Peterson was born, the oldest of five children, in 1934, when the depression was in full swing.

Conformity with expectations of how a mother 'should' be a good housewife gave Karen's mother little scope to express herself, and she struggled to conform to the ideal. She lamented how, with the rigid schedule of feeding prescribed for Plunket mothers: "I starved you Karen, I starved you. They made me feed you only every four hours" (3). It cannot have helped that Truby King, who strenuously promoted Plunket and the cult of domesticity, farmed a mile or so from the family.

By 1940, and two sisters later, Karen's father again obtained a small farm, and farmed it part time while continuing with the rabbit board and sawmilling. These were rich rewarding years, as her mother encouraged the children to paint and to explore literature extensively. Two more children arrived and the children of the family, a mile from anybody else and without transport, were their own social group; "it was close, it was loving but there was also a good deal of sibling rivalry and fighting too" (3)

School in nearby McLennan had a small roll: between 15 and 25, and was closely intermingled with the community in which it was set. When the polio epidemic of 1942 spread to the community, most of the children of the school, including Karen and her sister Gwytha, had diarrhoea. More seriously ill was third daughter Beth who, Karen says, and in retrospect, probably had polio. Beth required much attention while the two older girls were in bed, 'recovering'. But instead of recovery, Karen suddenly developed alarming symptoms of polio. When a doctor was obtained, she was rushed to Owaka Cottage Hospital, in pain and paralysed in the legs, trunk and right arm.

Debate about the best method of treatment for polio was widespread at this point, and Karen's doctor did not support a new form of treatment, the Kenny method, which involved hot baths and passive exercise of affected parts. So she had very little actual intervention beyond "bed rest and a general encouragement to move when I felt like it" (7). After three months she began to walk: general encouragement became a medical order. After five months she returned to the family home for Christmas, with the family increased by a brother.

In February, Karen returned to school, and found that this meant considerable fatigue, particularly since she had to walk a mile between school and home.

Overwhelming fatigue was a very noticeable after-effect of the polio, she also was sensitive to noise and temperature, lacked strength and coordination was limited.

The attitudes of her classmates caused Karen some distress. Her physical weakness and timidity made her the object of bullying as other pupils made a circle around her and "they'd give me not too painful a punch, but try to get me to hit back" (10). Worse still were the effects of fear on her relations with other children. People didn't know how polio was transmitted, and thought they would catch it from Karen. Hence they avoided close physical contact with her, and if they touched her would leap back saying 'ooh hoppers', to avoid the germs she carried. To Karen "that really bit the deepest" (11).

After two years [1944], Karen's parents who had become, disillusioned with orthodox medical treatment, thought that her recovery could go further. That year she spent one day a week in Dunedin and went to a chiropractor. The effect on her general health was of benefit, and may well have relieved her parents too. To external appearances, she had regained considerable function. It was not a complete return, and she remained a marginal participant in sporting activities. Her classroom work was much at the same level as before, despite the absences, and that fatigue limited her participation.

At 16, Karen entered and won an essay contest about world peace. She had never forgotten the first newspaper pictures of the atomic explosion at Hiroshima. The prize was representing New Zealand at a world youth forum in England. Although it was a very enjoyable experience, it was an exclusively white gathering:

> The penny didn't drop till decades later, there were no blacks or Chinese, that every single delegate was white Anglo Saxon except a lovely boy from Jamaica who was quite dark and said he had gipsy in him. Had to explain his darkness.
>
> (20)

The departure to England was combined with a visit to Silverstream's Polio Hospital in Wellington to learn the Kenny technique.: Karen's mother was still not satisfied that all possible physical rehabilitation was achieved, and they learned the techniques of twice-daily hot baths and stretching exercises.

Back at Papetowai, the practice of this technique, in combination with the trip to England put Karen further into the centre of family attention, and "all the other noses in the family were fairly much out of joint at the time" (18)

After leaving primary school, Karen did correspondence schooling until her last year at school. While this was a practical decision, based on distances and costs, it was a style of learning that Karen found very good. The learning was quick and concentrated and "once you try all those tricks and get over them, you've got to learn. And it's one to one learning then. You cannot hide in a class and pretend to be listening" (14). It was of further advantage that trying playground episodes were absent, and learning could be fitted to her highs and lows of energy.

Correspondence school had regional gatherings and there Karen met other disabled teenagers. She did not consider that she had anything in common with these others, who had birth disabilities. But she did make a link between the expectations that others had for them and the kinds of opportunities or lack of opportunities they were experiencing. Thus in one young man with a very protective mother, Karen could "see the resentment on his own face. And I could see that guy was never going to achieve" (28)

Country schooling had tended to encourage equal participation of both sexes in all sporting activities. Behaviour in the playground, good and bad, was evenly distributed between the sexes. However, Karen's teachers retained a gender bias

in terms of what the girls were being trained for: "housewives, teachers or nurses when they grew up" (13).

Karen experienced a different approach to this, when she took part in correspondence schooling. Her mother listened to many radio programmes, heard of all the things that people were doing "out there", and saw the many possibilities for her daughter other than teaching or nursing. She kindled Karen's imagination, and encouraged her to explore widely. When Karen attended Otago Girls High School, in her last year, Karen had a list of seven non usual possibilities. They including law, horticulture and journalism. But the vocational guidance counsellor had different ideas, seeing Karen's disability as a barrier to her work in any of them: she would not be strong enough.

The counsellor's suggestion was part time library work. An advantage to this was that she would be able to finance part time university study. A greater range of books was also on hand, and this was a considerable advantage as Karen was reading widely and "preparing my own values" (21) The vocational guidance counsellor arranged for the job, and somewhat reluctantly, Karen began. But thereafter, she was consumed with a desire to "get out of the place where I'd been sent because of my disability. I wanted to get, to go somewhere on my own right" (23).

She was also aware of her "restless, driving, curious" disposition (19), and found the job was not sufficiently stimulating. In addition to a need to feel stimulation, Karen had a strong sense of being a part of a broader picture, which meant she needed to be socially active. When these elements were combined with a desire to run her own life, change was likely. After three years and two thirds of a degree, she left Dunedin for a journalism cadetship in Taranaki.

Her restlessness had been exacerbated by a relationship that came, she felt, too close to marriage. Although she lived in Dunedin, Karen retained close links with her family and home community. She spent much time at home, and when she was 20, was "courted" by the local schoolteacher. He was a "strong, personality, charismatic...a real man's man with the boys" (16). This made her cautious, as she saw excessive mateship as a danger signal. Karen was unsure until a drunken proposal in front of everyone at her 21st birthday clinched her decision to finish with him and to move into a change of career.

On arriving in Taranaki, Karen was keen to learn more about Maori customs, but found that social interactions between Maori and Pakeha were not widespread. On the newspaper where she worked, however, Maori occupied a number of senior positions, and it was gender rather than race relations that were difficult. The editor told her on her first day that "it wasn't <u>his</u> idea having a woman cadet. 'I got overruled. I got talked into it' " (22).

So while she was paid at the same rate as male cadets:

> I was not allowed to gather news in bars, in public bars with men. And I was not sent up the country to Taumaranui, which all the other cadets got, because I wouldn't be able to handle the rough people up there. (22)

Instead, she was given stories on women's organisations and minor sporting organisations, and occasional contributions of recipes for the women's page were requested.

If gender and employment proved difficult in this job, disability was so impossible it was almost never mentioned. She was aware that this job prejudice existed because:

> I never saw a person with an obvious disability serving me in a shop, or if I had to go into an office for any reason, being there...really I think it just seeped in through my pores. I mean, just like I came to Wellington and

never saw a Maori serving in a shop ...You get your message from that, don't you? (23-4)

Karen had become particularly sensitised to job prejudice against disabled people in her previous job. Library work had been "part of the myth of what people with disabilities can do...you know we had our ghettos, our occupational ghettos" (23). She was keen to break free from ghettos, and knew enough about job prejudice to not want it in her life "I was going to fit in" (25). She therefore didn't mention disability: "I was busy passing at the time" (22). Apart from the difficulty of carrying her very heavy 'portable' typewriter to assignments, and periodically falling over at somebody's feet, she "thought about my disability as little as possible....I thought 'normal' because, you know, rehabilitation's meant to make you think normal" (25).

It came however at a cost.

> You did have this guilty feeling that you were hiding a guilty secret because you yourself thought that you were defective. Its only in the last 20 years that I've actually come out of feeling that there was something fundamentally wrong with me as a human being. That I, you know, that I had parts of my humanness missing.(27)

After two years, Karen moved on and in 1957 went to Wellington as a publicity officer for CORSO. Although she enjoyed the work, the call of teaching was strong. The medical examination which had been compulsory had been abolished. She was thus able to apply for, and gain a place at Christchurch Teachers' College in 1958. After one year in Christchurch she transferred to Auckland for the sake of her circulation.

Through one of her new flatmates she came to know a young Samoan man with whom she fell in love. At this time [1959] contraception for women, particularly single women was rare, and men did not use, or could not easily obtain condoms.

Despite a determination to obtain contraception, as the University's doctor was more liberal than most, they moved into a sexual encounter before it was obtained. From this episode, Karen became pregnant.

Karen was aware that abortions could sometimes be obtained illegally, but were usually expensive, backstreet and risky. She also knew of some self-induced methods ranging from gin, hot baths and violent activity to knitting needles coat hangers or ergot. While she considered the less risky 'folk' methods, the more dangerous methods were excluded. She now faced pregnancy outside of marriage which attracted widespread censure, in extremely difficult circumstances. The father of her child had just finished an engagement with a woman of whom his whole community approved, but when the woman found she was pregnant, he decided to marry her.

When her pregnancy became known, she had to leave Teachers College. All of those with whom she had contact-family and friends "all assumed I was going to have it adopted"(33). Her parents also urged adoption, but because they were "just terrified that I would have a complete sort of physical breakdown if I tried to walk around carrying a baby" (33).

There were few avenues of support before birth for young women who were not adopting after birth. The Salvation Army would not help when Karen would not promise to give her child for adoption. She eventually found an organisation, the Motherhood of Man which did not insist on adoption. They helped by organising a live in domestic positions and travel to hospital at birth.

In the first few months of her pregnancy, Karen was able to work in a factory, even after her condition became evident. Her landlady was less tolerant. When she discovered Karen was pregnant, she asked her to leave, since "single girls pregnant were worse than having the plague in the house" (34). The general

intolerance of extramarital pregnancies meant that Karen's parents told nobody in the Catlins, and urged her to be careful in Auckland in case she was seen by family acquaintances, which would cause many difficulties for her family in their small rural community.

Following a somewhat difficult birth, Karen found another live-in housekeeping situation but it was not satisfactory, and after some months, she moved with her son to a flat in Wellington. From there, she arranged to return to Teacher's College in Wellington, and searched for child care for her son.

Child minders were necessary, as no reliable day care centres were available. Karen found that obtaining, then retaining good carers was difficult. However she was able to maintain sufficient overlap of carers and complete her last year of teacher training. Other barriers to her in her 'unmarried mother' status included that Teacher's College policies required her to change her name by deed poll. By such an action, any parent inquiring about her surname would assume she had been married and therefore was sufficiently respectable to teach their children.

Towards the end of that final year of training, Karen decided to marry a Maori man from the East Coast. They had met, in Auckland, liked each other, exchanged letters and occasional visits. He loved her son, and she was happy to marry. But he was seriously disturbed, and the marriage culminated in a "very traumatic" (40) episode where "it wasn't safe for me to stay" (40) She left, with her son and tried to resolve matters through letters and meetings. But this, and last attempt to sort out the problems of the marriage through the offices of local kaumatua failed.

At 26, Karen could look back to a very full year including pregnancy, teacher training and marriage. The net result of all the stress and trauma was that "I thought here I am not handling things particularly well: not doing wise things" (42). However, it was her relationship with her son which had become "the anchor in my

life"(42), and the outcome from the year was a greater sense of maturity, painfully gained.

She worked her first bonded year out of teacher training in Lower Hutt, where adequate housing at a reasonable price was very hard to find. Although she had joined the waiting list for state housing[60] her wait was long. As she waited, it "gradually became clear to me that there was a fairly long waiting list, but that 'respectable' families were getting there faster than me....I was still a pariah class" (43).

After almost a year, a state house became available, and shortly thereafter, the Hutt City Council began to provide a creche, greatly easing her childcare problems. Karen continued to teach, although she had severe concerns for the destabilising effects of constant changes of childminders on her son. She decided to teach remedial reading from home, separate from the state education system.

A consequence of using a Maori surname (an upshot of her brief marriage) was encountering prejudice. After people contacted her by phone and Karen had told them her surname:

> they would almost invariably pull out of the arrangement...they didn't know whether I was Maori or Pakeha, but I had a Maori name, and they didn't want their children coming to a teacher with a Maori name. (46).

Although there was need for remedial teaching, work was patchy and her existence frugal. She did occasional domestic jobs, and grew most of her own food.

Karen then found that the creche supervisor had been telling her son he was "a dirty Maori" (46). He became unhappy at kindergarten, then at school, when he

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[60] People on a low income could obtain rental of state houses, which were owned by the New Zealand Government. If they qualified, their names went onto a waiting list The rental was affordably low

began there. She decided to move to another area and, in 1964, managed to swap her state house in the Hutt for one at Linden. She also arranged to teach in a school again.

Karen's new position was to begin almost immediately after her move to Linden. But she had packed and shifted house almost unaided, resulting in a physical collapse, She could not obtain the time off work she needed to recover; her doctor preferred to prescribe tranquillisers rather than rest. She returned to work in an state of exhaustion, and subsequently had to leave the job to obtain the rest she required.

A brief period of casual work, which was easy to obtain, followed throughout that year and the next. Later, a visit to vocational guidance introduced Karen to part-time clerical work in the public service. It was only when a recession in the economy came in 1967 that she changed her position to permanent, which automatically entailed full time employment. At this stage the public service was a single entity, so movement from one government department to another was, she found, relatively straightforward. From clerical work with vocational services, she moved to editing, and thence to social research in the Department of Labour.

Karen's employment in the Public Service meant, after many years, good wages and working conditions. She bought the state house she lived in, and completed her Bachelor of Arts degree at Victoria.

She met her second husband at a Labour Party social function in 1972, and found a shared concern for people's social circumstances. The relationship became solid quickly, and they married the following year. It was, and has remained a very positive, and solid relationship. In material terms all income and property have been shared (51) and there has been an emotional sharing, plus a commitment to share parenting.

A time of consolidation and saving followed: both had secure, well paid jobs, and when goals of home ownership and extensions were completed, they turned to another mutually held goal: owning a kiwifruit orchard. They bought and began to develop their orchard while still employed in Wellington. This involved two years of weekend commuting and involved hard, manual work. By 1987 they were sufficiently ready to begin, and left Wellington for their "dream". Horticulture had been one of the seven non usual careers on the list Karen presented to the vocational counsellor at high school and she worked vigorously to put her dream into reality.

At this time her husband had been dealing with a number of chronic health conditions-kidneys heart and hips- and was in no state to undertake much exertion. Karen undertook much of this. But the exertions did not agree with her body either, and back injury resulted.

During the years of preparation, there also been some prior indications of post-polio syndrome, in odd twinges and muscle strain. Now, working the orchard full time, muscle weakness, fatigue, pain and inflammation of tendons flared again, over 30 years after the original bout of polio. The symptoms became too obvious for Karen to ignore.

Medical investigations finally gave a name to her symptoms; Karen had not heard of post-polio syndrome before. To her, it was a relief that "I'm not lacking in backbone. I'm not a hypochondriac. I have a condition that I have to come to terms with" (54) When she explored the condition, and realised that it was not temporary, Karen began to understand, then acknowledged that she had a disability.

This passage marked a considerable departure from her previous stance. For most of the time Karen had spent in work, both paid and unpaid, she felt unable to

acknowledge disability. She had felt pressure from society to be 'normal', to conform to accepted practices. She saw few people with disabilities in employment and the 'blend in' message was clear. To blend in, to conform brought safety, but the cost was recognition of part of herself.

As part of the acknowledgment, she began to wear a leg brace in public, then use a stick in public. A more open declaration of disability came when she became involved with the Post Polio Society, and started to collect material to edit a book on polio survivors. To her, this was a "very self affirming activity" (56). The process took several years but it had the effect of making "me realise far more of the common oppression that people with disabilities have than I had actually realised in my own experience" (58)

Karen grew more aware of what a state of disability meant to her, and she became involved with disability organisations such as the post-polio society, and DPA. She began to form an analysis of disability. For most of her life she had supported non discriminatory behaviour and spoken out on issues of justice. She had socialist attitudes and had studied sociology. So she was readily able to speak of disability in terms of oppression, and support social models. She rejected the constrictions imposed by conceiving disability in terms of normality, where "everybody thinks we're the abnormal ones and its our problem" (58).

Karen regards her commitment to justice as "one of the main keys to my personality" (59). She has set her understanding of disability alongside the other issues of justice that she continues to support: poverty, age, racial discrimination, sexism and disability discrimination.

As she and her husband age, income and assets have again become again important, as they were when she was single, pregnant and without financial support. Although there are now some assets, in the form of land and house, there

is little cash. Neither has enough health for the manual labour needed to maintain an orchard but they are not old enough for Government Retirement Income. Further, the issues of poverty and age overlap with disability, as poverty means that aids and equipment may well be unobtainable. Karen is very concerned with the principles of equity that she sees as part of the issues of support services, but which she feels are not being used.

Karen has come to take greater control over the management of her impairment through the use of carefully targeted exercises, to improve muscle balance. Although this style of exercise has improved her options, she is conscious that she is "fighting for your present level of ability. And I am, because since I did give up full time orcharding, I've been on a plateau with a very slow deterioration" (62).

The possibility of disability and aging combining in a lessening of capacity is a disconcerting concept, as a lifetime of adapting to difficult circumstances has built a tendency to accept nothing less than triumph. So Karen felt:

> "We could, with great, with enormous amounts of effort, pain and fatigue, we could climb up a little way, and it is as if we were on a ratchet, you know....Things were going to stay- if we got ourselves better we stayed better and we, whenever we were bemoaning our lot, we would say 'well isn't it a lovely thing. Isn't it great'. We relied on it as a prop of our emotional state of being" (65).

Karen has gradually become "not as afraid" (65) of dependency, accepting that use of stick and splint has made life easier. The "little voice in my head" (67) that pushed her on for many years has gradually been quietened,. Now she has more control over her body, manages her levels of fatigue better and this makes her more at ease with her circumstances. She still retains her passion though: she is editing her second book, writing poetry, and contributing newspaper features on a regular basis.

ANN BALLIN

Ann has lived large portions of her life in the public arena. She chaired the International Year of Disabled Persons, was a commissioner to the Royal Commission on Social Policy and chaired the Victims Task Force. She has practised as a psychologist for almost 40 years. As she has undertaken these public positions, she has constantly attended to financial security. She built her first home when she was 32; a rare achievement for women in the 1960s. She ensured that her mother's environment remained comfortable and undisturbed. Home, family and family history are important to Ann.

Ann has an evident talent for telling stories from life experiences: it is so well developed that stories she has told on other occasions are retold with freshness and conviction. Her sense of connectedness with the stories of her family is very strong.

Ann's parents were "the hippies of their day" (1). Theosophy, vegetarianism, sandals-wearing, socialism and classical music were not common ingredients in married life during the 1920s. Neither did conventional fathers with small daughters abandon a safe career in management to study medicine on the strength of a small heritage, as Ann's father did.

Both parents came from families in which vigorous and strong-minded behaviours were common. Her mother's mother had eloped to Northland from her Australian home with a Cornish gold assayer. When four children had arrived and the Cornish assayer died in an influenza epidemic, Ann's resourceful mother supported the family on her earnings while her mother (Ann's maternal grandmother) endured a prolonged bout of severe depression. Life was hard for the family: "They lived in Franklin [suburb of Hamilton] in abject poverty. My

mother was the only person who earned any money between the two families who lived side by side" (2).

In Ann's father's heritage there was also vigour and independent thought. Her father's grandfather came from North German Jewish stock, migrated to Aotearoa/NZ in his teens, and set up a cordial factory at the Thames goldfields. He later moved to Christchurch, where he imported wines and spirits, enjoyed horse racing, helped to build the synagogue and a Catholic orphanage and supported surf lifesaving. His daughter, Ann's paternal grandmother, took the unusual step of marrying a cousin: "maybe there was a paucity of Jewish men" (1). When she later divorced him and subsequently married a hotelier it was even more unusual, even scandalous.

Her father demonstrated his capacity for independent thought from an early age. While he was still at Wanganui Collegiate, he refused to attend prayers because he was unsure of the existence of God, and this was not well received by school authorities. He later became and remained a staunch socialist. The depression of the 1930s had a profound effect on him: he had remained in employment in Hamilton, but the suffering he saw among people at this time moved him strongly. When he inherited some money, he moved to a career that seemed to be more consistent with socialist ideals: medicine. His wife also supported socialism, and his dream of medicine: she supported the family while he completed his medical training through whatever paid work she could find.

At Ann's birth in 1932, it was soon apparent that something was awry in her spine. Before the family went to Dunedin in 1936, a specialist in Sydney had apparently diagnosed then fixed a dislocation in one of the vertebrae. But during their time in Dunedin it became evident that there was still a skeletal problem. Ann had a very distinctive sway back, so that "I do recall jumping down a step; I must have been about ten, thinking to myself 'you are like an old lady' because I had lost the

spring" (6). The usual shock absorption action of the muscles was absent. Her foot dragged, and a side to side curvature of the spine developed. Walking became increasingly difficult, and was by the time she was 13, Ann could no longer walk.

Ann found what was happening to her a complete puzzle. The appearance of the spinal curvature called scoliosis had not been sudden, and the resultant difficulties came as "a series of little catastrophes" (7). At the time, little was known about the condition, its consequences and what were options for treatment. The lack of knowledge about the condition, combined with a lack of information upon which decisions could be based meant that it took her over a decade to regain control over her own life.

Ann saw the time of unknowing as dreadful. Not only were there no apparent options, but the medical personnel "just didn't understand the psychological impact....They couldn't see the impact on a child of long hospitalisation, of being deprived of normal adolescent socialisation, of all those things" (7).

Like Ann, her parents were given little knowledge, such as what could be achieved with physiotherapy, and were left to deal with their own feelings; they were in little state to support Ann and her feelings. They didn't cope with the issue, and, as a consequence, tended to treat her as nothing other than ordinary. Indeed, Ann's mother had an emphatic dislike of "pushy disabled people" (12), which gave little room for Ann to be any different from anybody else. But Ann also commented that because her parents didn't treat her differently, they didn't always see the things they might have done to alleviate problems she encountered.

Ann's schooling, up to this point, was in private schools, with the fees paid by her father's mother. This was first at a Montessori school, then at St Hilda's Collegiate in Dunedin. In this period she discovered herself to be an intelligent person. But when she was 12, shortly before she was no longer able to walk, her formal

schooling finished: there were family troubles of an unspecified nature. In the teenage years that followed, she tried to study through the Correspondence School, but this was not successful. She reflects that the method was not successful because "I'm not a person who works independently. I like to have people to help me to do what you have to do" (7). At that point, her education had not developed in her a capacity for working on a task individually.

Her focus drifted instead to teenage preoccupations with pop records, and magazine stories of romance. She became expert in the ephemera of the lives of famous 'stars', and in lyrics for the popular songs of the period. When romance literature palled she moved to more classical literature such as Jane Austen.

Through her teens to her early twenties, Ann was not involved with any formal schooling. Despite this gap, Ann retained awareness of, and faith in her intellectual capabilities. Her father completed his training and the family had moved to Auckland. After a sister was born in 1952, Ann began to plan for further study of some kind. A brief period at a coaching college ensued. While this phase was not enjoyable, the end result was satisfactory, in readying her for university study. She enrolled at Auckland University under the study provisions for adult students, and began to study for a degree in education.

University studies were made more difficult because of problems with access. University buildings, like most buildings at this time were not physically accessible. There were no ramps, and when Ann was unable to get into a room or lecture theatre because of steps, it was necessary to carry her. Since the site of the University of Auckland site was very hilly, and had many stairs, a lot of carrying was necessary.

Until that point, the principal way she had moved around was by being carried by her father. Such wheelchairs as existed were large, cumbersome and pram-like.

When the Ballins saw one of the more modern design of wheelchairs, which had tubular frames and were collapsible, they promptly obtained one for Ann. It allowed for independent movement. But Ann still required transport. Her father drove her to and from the University around since "There were no wheelchair taxis, and ordinary taxis would have regarded having to put a wheelchair in the boot as a bit of a problem" (8).

Access barriers also existed in relation to information. Universities expected that individual learning was the accepted way to undertake university study, but gave little thought to the way the information required by this approach might be obtained. Much of the information was sited in the university library, but Ann found libraries were difficult to get into, then to use fully.

These were ongoing difficulties constituting both physical access and inimical attitudes. The physical barriers were that "if I wanted to, I couldn't get in, and I didn't know how-I wouldn't have been able to reach the books, and things weren't built for wheelchairs" (11) The inimical attitudes are encapsulated in an experience at the University of Canterbury where "I remember the chief librarian telling me-I was at the desk one day in one of my rare efforts- and she said 'You're in everybody's way Ann'" (11).

She completed half a degree at Auckland, then, in 1957 a small insurance policy matured and she took a brief trip to Australia to see Margot Fonteyn dance. Ann came back to New Zealand with renewed determination to finish her studies, and a clearer sense of her course of study. The family moved to Christchurch, and she enrolled there to complete her degree, sampling law papers, and finally majoring in psychology. The university site was flatter, she had formed satisfying friendships and she enjoyed this period where she was "a kind of common-room lounge lizard" (10). It was, to all intents, a period of adolescence.

At the beginning of the 1960s, in which Karen remembers a high level of conformist attitudes, daily university life often showed a careful sameness. There was little money to spare in the circle of Ann's student friends, and the invalid's benefit which was her means of support was used carefully. An acquaintance who owned a car "was regarded with great suspicion as being 'spoiled' and a bit above himself. Yet Ann used cars and taxis daily with no sense of extravagance There was no real alternative for her. Transport was necessary, and accessible public transport did not exist. Since taxis would now carry people using portable wheelchairs, she was able to use these as well as being driven by her father.

Ann completed a degree in psychology, followed by a masters degree and professional qualifications for clinical psychology. The post graduate period was extended as requirements kept changing, but finally in 1964 she finished studies and took up a position at Princess Margaret Hospital in Christchurch.

Ann saw how conventional attitudes towards women and reproduction did not hold for women with disabilities. The expectation of love, marriage and children to which women were expected to conform was not held for her, although in her twenties, she had thought she would like to marry. But she also saw that nobody else thought she would marry.

Neither was it expected that she would take part in any sexual activity. In pre-oral contraception times sexually active women were fewer in number, as the possibilities of pregnancy and social obloquy were higher: as Ann recalls, "we were all terrified of getting pregnant" (14). But sexual relationships for disabled women were regarded with horrified disbelief, as some kind of obscenity was contemplated. Ann encapsulates this attitude as "what sort of a man would want to be involved with a person like that, I'd like to know?"(14).

This attitude was not universal though. Ann also encountered a different current of thought among some young men. They explained to Ann that sexual activity, albeit without the usual context of marriage, would be beneficial activity for her. It was unstated, but apparent that such an occurrence would satisfy some curiosity. She encapsulates this as:

> Only the body beautiful would wish to be sexually involved. And I did encounter some unfortunate situations where young men would regard you as a bit of a challenge, because they had never involved themselves before with a disabled person before. And they'd say it, which was really interesting....I think they thought it was going to be good for me (13)

She was not dissatisfied that marriage seemed to be out of the question as far as other people were concerned:

> I now believe that I have been, I was preserved from it. I think that I might well have made a bad marriage because my standards would have been far too high to be met....And now I have absolutely no regrets what-so-ever (13)

Other men, both at this time and later, were more direct than the young men who felt that sex would be beneficial for Ann. They were, nevertheless, given to strange or offensive ideas. Ann attended a workshop in an inaccessible building, and required to be carried up and down the stairs. A visiting psychologist commented to her "you get a lot of secondary gain from having these men carry you upstairs" (17). And one of her supervisors, who conducted classes in an inaccessible building said that the carrying in-and out constituted a sexual involvement. To deal with this situation, Ann took to counted thread embroidery as "an obsessional activity to deal with the rage that I felt for him. I was really enraged because I was helpless" (17-8).

The care which Ann felt for financial matters arose, in part, from her life with a father seen to be "improvident" (27). Ann's mother had been the sole wage earner for two very poor families before she married, and had retained a sense of thrift. However that sense was not part of her husband's heritage: his relaxed and liberal attitude to money meant she encountered considerable difficulties in making ends meet. Ann saw her father's "total incapacity to handle money" (21) over a number of years and this had its effect. It meant that she didn't squander money, carefully saving it. She did not intend to "end up like that" (21), and focussed on security That security included provision for her mother after her parents separated.

Given this focus, it is unsurprising then that Ann built her first home in 1964, and has owned her homes since then. At the time, it was not common for women to own property in their own right. But she was in an uncommon position for a young disabled woman: she had professional qualifications and employment that was secure and well paid, so she obtained a mortgage. The bank required that women had two, rather than one witnesses: the extra man was expected to be sure that she understood the contract, but Ann gathered that an extra witness was required for any woman who took out a mortgage.

When Ann's mother and father separated in 1972, Ann's mother felt the time was right: Ann's sister had just left to study pharmacy. Her mother now ran the household while Ann was the breadwinner. They lived together until a year before her mother's death in 1994. During that year, Ann "really began to live on my own you know, in spirit" (14).

Such living arrangements had proved satisfactory. Friends remarked on the closeness of the relationship between Ann and her mother. That it was so is a source of many differing feelings for Ann. There is some bafflement, because at times there were battles of will and Ann was confronted by her mother's seeming intransigence. She was also happy that their closeness was so evident to others.

There is also a wry recognition of certain less developed aspects to the relationship: emotional support was less evident than concern for meals.

Although her mother lived in her house, Ann did not relinquish a close relationship with her father, whose sense of humour she appreciated. They had long been close, and continued to share each other's affection. In 1976 her father died, and the warm memories remain: "he died twenty odd years ago, I still think 'oh he'd like this' "(15).

From 1964 then until 1981, Ann worked as a psychologist, hospital-based until 1974. After 1974 she was at the University of Canterbury, in Student Health Services. In the beginning she encountered stereotypes where doctors did not believe she would be a competent psychologist because, as a disabled person, she "will have problems of her own" (15). Other psychiatric hospital staff felt Ann would be unable to work because she was disabled and therefore was vulnerable to attack. She feels this is representative of the time, and of an earlier belief among psychologists and psychiatrists that they knew how to live and "that they could do it better than anybody else" (15).

However, she also noticed negative attitudes to disabled people were more widespread than in just one group of individuals who were sure they had the answers to living properly. In a meeting she attended about crippled children "all the decision-making was done by able-bodied people, and they [the disabled children] were kept well apart...that's the sort of attitude there was" (16). She has tended to find ways around such obstructive attitudes, rather than to confront them head on. Thus, later, at Canterbury University, she instituted practices to enable blind and dyslexic students to complete assignments and exams in ways that suited their needs.

She kept actively involved with her professional association, and was the first women's president of the national association. Through this position, she became known at a national level, including to members of parliament such as Marilyn Waring. In 1981, the International Year of Disabled People, Ann was appointed by government to chair New Zealand's committee as a result of Marilyn Waring's recommendation. From this point on, she became widely known, and called on for public appointments.

She described the year's impact in New Zealand as satisfying, pointing to the good groundwork provided by the standard for disability access in public buildings, NZS 4121, and the 1975 Disabled Persons Community Welfare Act. Her return to psychology lasted until 1986 when she left Canterbury University to become one of the Commissioners of the Royal Commission on Social Policy, then to be the first Chair of the Victim's Task Force. But between 1981 and 1986, chairing-level positions with the Council of Recreation and Sport, and the Hillary Commission were additional to her main paid work.

As she became a public figure, Ann encountered the full extent of appraisal of public figures. She found that some people misjudged her attitudes. She had been aware that the physical existence of a wheelchair does not allow its user to be unobtrusive, "you can't just float into the back row somewhere and not be seen. You can't be anywhere without being obvious" (11). Now this state of affairs appeared to have a verbal equivalent in being regarded as "opinionated and bossy" (11). She also found that she was seen by conservative people to be radical, and radical people to be conservative (11). Others felt she was enormously ambitious and liked to be in the public gaze.

Ann rejects this perception of ambition, saying that she never ever did a public job that she was not asked to do. As an explanation of why these positions came her way, she believes her lack of attachment to any particular position, is seen to

indicate her neutrality. That lack of 'baggage' has made her an asset in many official positions, and appointments have ensued. However, the attribute has been interpreted as ambition, and this was a particularly undesirable characteristic because she was female.

Of those public positions, her memory is, in contradiction to this public perception, of constantly stretching to learn the new skills required: "I had to learn to do these things, even although I was terrified" (22). It was stimulating to Ann, and she points to how "I never sought to do these things, but when I said yes, I said yes because I wanted to see what it was about" (22) The consequence has been that a "fascinating" life, although it has gone anything but the way she had imagined.

During her time with the Royal Commission, Ann developed considerable respect for the process, and for the people involved. She "was much more conservative than most of them, but I saw the wisdom of it, and I enjoyed it; it was interesting being part of that whole consultation process, of being in the middle of the turmoil that it caused" (24). By comparison, she found the Victims Task Force to be deeply involved with a Public Service ethos. It was difficult to avoid being caught up in the many different agendas and arguments, which made it difficult to keep to the purpose of the Task Force. After her paid work with the Victims Task Force finished, Ann "retired" in 1993. But she has since taken up further considerable amounts of "committee stuff" (27), which she regards as work, and valuable. She still undertakes a small amount of paid counselling.

Throughout all these public roles, Ann's mother continued to regard her as a completely ordinary person. When Ann was made a dame, she was somewhat bemused, and "couldn't see quite how ordinary old Annie had ever risen to such heights" (12). She had little interest in the kinds of issues with which Ann was dealing, and a consequence was that home was not a place at which Ann was able to talk through her feelings about her work.

The circumstances in which Ann undertook work led her to think more about the context in which work takes place, the big picture. While her orientation was basically conservative, she came to understand that "I don't fit in the view of modern market-type philosophers. I grew up in a socialist state, believing we all have a responsibility to each other" (26).

On a more group-individual level, work has had a dominant place in her life, and she has also thought about its significance, beginning by saying what it meant to her "It meant respectability for a start. It meant independence. It meant being stimulated and not stuck someplace, powerless"(25). She is equally clear about the applicability of this: "That's what I would wish for all disabled people" (25).

Ann has also been close to the complexities of caring. When she was young, her parents provided almost all of her caring needs, and this continued to a more limited extent throughout her life. But as she reached her sixties, she began to provide more care for her mother, while she still had caring needs herself. Because Ann has had long periods of well-paid, stable paid work, and she has been careful about saving money to provide for her age, she could pay for most of the support services she required, in order that she could then support her mother. This was able to be maintained until six weeks before her mother's death, when hospital-level care was necessary. Even then, Ann continued to provide care for her mother, travelling from her own residence to the hospital to provide the food that her mother would choose to eat .

She has become increasingly aware that the time may come when she will need to live in some place other than her own home, with greater levels of care, and corresponding constriction on her capacity to make choices. Ann views the prospect with dislike, and vows "I'll have to be really struggling before I do it" (28).

At present she can make choices: about maintaining her own house and garden, eating the food she wants, and going to the occasions she chooses.

Ann is very conscious that she is in a good position to make choices in relation to her support needs. She attributes this to a combination of factors; her intellect, her middle class background, hard work and luck. She is aware that the position she is in is:

> ultra privileged. I sit in what is really a beautiful home, in a beautiful garden and, at this moment, although you never know what's around the corner, I have a fairly smooth-running existence. I do what I like, when I like, how I like and with whom I like, and there are not many people who have that kind of freedom. (31)

SOPHIA WEST

When Sophia chose to train for marine engineering, World War 2 had just finished, and she only knew of three other Scots women in the occupation. So it might seem like she had made a bold move that challenged conventional concepts of women's work. But that wasn't Sophia's way: her upbringing was middle class and conventional in its values. The world may well have been changing, but when it came to male-female roles in lowland Scotland, Sophia did not see huge changes from what had gone before, and she did not decide to take on an unusual occupation to challenge traditions.

Rather, she decided what mattered, then moved to achieve what was desired, with a minimum of fuss, and a maximum of resolution. This practical approach was characteristic of the way she dealt with other, later, choices or issues.

When Sophia was born in 1931, in Eastbourne, England, conditions associated with the economic depression were beginning to bite. Her father had alienated his employer on his marriage in 1929, and paid work was scarce. After a period of finding temporary, transitory jobs her father found a permanent position shortly after her birth. However, it meant a move to Glasgow.

The family moved into an apartment in the tenement buildings that were common in Glasgow. Tenement buildings differed in quality. At the basic end of the scale were the 'single end' buildings, comprising one half of a floor as a single room and shared toilets on the landings. These were the type of tenement buildings that were in the notorious Gorbals[61] slums, and they were far more basic than the tenement building Sophia's family occupied. Even so times were hard, and those

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[61] The Gorbals were a notorious block of slums in 19th and 20th century Glasgow. Of the single-end tenement buildings, they were the poorest. Facilities were virtually non-existent, and the area was characterised by poverty and ill health.

who could not afford rent slept in the streets. Sophia has vivid memories of the families in the streets, and other effects:

> It was the children I remember mostly. Especially in winter, when you had the slushy icy snow on the ground and busy streets, and these kids running around barefoot, their trousers with holes in them, so that their backsides were poking out. Their jerseys with no elbows in them, and their shirts were dad's, obviously cut down ones because they had no collars...it was painful to see. (5)

During the depression, there was a constant stream of beggars and other destitute souls to their door. Sophia's father and mother ensured they at least got a cup of tea, but their practically-based social consciences could do little more.

She was the only daughter, and adored by her father, who had wanted a little girl. However, her birth disappointed her mother who wanted another son as there had been few in the family. Her mother's mother, herself from a prominent New Zealand family, had separated from her well-to-do husband in New Zealand, and gone with her young daughter to live in England ("home"). In her circles male children, heirs to the family name, were prized so it is unsurprising that Sophia's mother displayed this attitude. It was, however, hard on Sophia. When, later, a younger brother was adopted, both boys received much attention: "made a great fuss of" (7) by their grandmother and mother. Sophia believed she was not loved much because she was female, but revealing her suspicions to her mother, much later in life, brought forth denials and violent recriminations. But love from her Danish-born father was unambiguous and constant, and Sophia felt a life-long bond with him.

Although Grandmother focused on the primacy of male children, she paid great attention to education, and its importance to both sexes. She wanted her grandchildren brought up "correctly" and the state education system in Scotland was seen as inadequate. She called Scotland the end of the earth where all the

savages lived. So grandmother paid for Sophia and her brother to attend select private single-sex schools. This private schooling was a dominant theme, and continued even through the war time years, when evacuations and bombings of Glasgow caused great disruptions. When she, her mother and brothers was sent to the countryside, schooling continued at a small private country establishment. After the worst of the bombardments had diminished, they returned to Glasgow, and schooling continued, but in a sporadic manner.

For Sophia, another factor to interrupt her schooling was bouts of sickness. From early days, allergies were present, and she was aware of having psoriasis from when she was 8 years old. The presence of these conditions appeared to engender a greater-than-usual susceptibility to the illnesses brought with the waves of people from other countries: soldiers, sailors and refugees. They brought new strains of what seemed like every kind of contagious illness imaginable. By the time the war was over, she had large gaps in her schooling; she estimates she may have lost as much as 3 years in total. She went, at age 14, to a private coaching establishment.

It was at this establishment that she came into contact with numbers of disabled servicemen most usually amputees. She also saw, up close, the adjustment difficulties of returned prisoners of war, and heard eye-witness accounts of Hiroshima. Knowledge of these 'gifts' of war was added to what she had experienced of the air -raids and to the stresses her father's job as a policeman entailed: he often pulled bodies from the ruins after a bombing. In total, her experiences gave her a life long passionately-held aversion to guns and war.

War time duties brought a number of the traits Sophia's mother possessed to the fore. She was reserved in public, though Sophia experienced her as authoritarian within the home. But as well as reserved, she was calm and a very competent organiser. Thus her position as a street warden during the bombings suited her

skills well. She became less stiff in social situations, and received positive recognition for her work. In addition to these duties, she ran the family's delicatessen shop single-handedly throughout the war while her husband was in the police force. Stocking as it did a range of "foreign foods and spices...and various things from wholesalers" (11), the shop became a centre for many refugees, soldiers and sailors. Sophia's mother made all of this possible.

Sophia's mother had a positive belief in herself, and in her daughter's ability to achieve what she wanted to do, encouraging Sophia in independent, competent, decision making. When it was time for Sophia to consider her career options, her mother was positive and encouraging-"well dear, if you want to be a chemist or architect or lawyer, let's go ahead; let's find out what that entails"(14). Although she was conventional in a social sense, she clearly believed in her abilities to manage and decide, and believed her daughter was likewise capable

Her encouragement was to have great influence. Sophia did not go to University; at that time preference was given to demobilised servicemen for places, and it was difficult to acquire the high marks necessary for the few available places. Sophia considered her options, and chose to complete a marine engineering apprenticeship. The choice was certainly out of the ordinary. Unions and engineers alike regarded the occupation as a male preserve, and few other women in Scotland had completed a marine engineering apprenticeship. But within the family it raised little comment. Sophia's mother and father were both pleased because Sophia was doing work she enjoyed. Any other considerations were of little significance.

Sophia is aware that the choice was unusual, but does not invest it with any barrier-breaking significance. Rather she points out that there were more significant events that were acting on people's lives. She goes on to set her unconventional occupation within conventional male-female relationships where

women "knew our place" (19) and followed conventions and appearances. She says:

> I think we make more of it today than what we did in our day and age. You've got to remember we lived in a topsy-turvy world. We'd had the great depression, thousands and thousands of people out of work. We then had the most awful war that the world had ever known. We were subject to rationing, to bombing, um, to invasion of foreign troops billeted in our city, and all that led to. We had a very strange upbringing, compared to what's happened since then. And it leaves its mark, but you don't look at these things as being history making, or breaking new ground, It was just a path you trod. Other people trod different paths because, for the reason that's what they wanted to do, and that's what they got the opportunity to do. (18-19)

She remains unimpressed by anything her action might be seen to symbolise, and had little time for women's liberation: "Germaine Greer, feminism and all that rot" (19). But her actions then, and later, of a woman acting and thinking independently, in her own interests had much in common with the feminist principles that Germaine Greer spoke about.

In this world-turned-upside down then, male-female roles seemed to her to be unchanged. But there was an explosion of high spirits among young people, relieved that the war had finished. Groups of young people were exuberantly, noisily evident. Sophia remembers clattering through art galleries, bouncing on and off moving trams, giggling incessantly, taking part in dances, going to the cinema and sometimes, daringly, smoking or drinking at parties. She saw it all as fun, letting off steam, and harmless.

While Sophia enjoyed the fun times, she still was perplexed by the intricacies of teenage relationships. Her schooling had been in a single sex environment until she was 14, and she was not well prepared for the concurrent arrival of "boys" and

the hormones of puberty. While glamorous stars like Michael Wilding or Vivienne Leigh portrayed romanticised models in the cinema or in magazines, the reality was more tentative and awkward. Quite apart from feelings there were practicalities, such as knowing how to kiss when "you're not quite sure where to put your face" (32).

There was one other factor though: Sophia had extensive psoriasis, and potential relationships were more complicated. She felt herself to be disfigured and unworthy, and she covered most of her body so that it wouldn't be evident. She was cautious about intimacy, and felt that she was not an attractive sight to a potential partner: "if the relationship was going to get any closer you backed off because you didn't want them to realise that underneath your clothes you were a hideous mess, "'cause that's how you viewed yourself" (27). There was a gap between the romanticised model and the everyday reality that she readily acknowledged, but dealing with a condition that was not picturesque proved to be more difficult. While one might talk about romance or beauty creams, one didn't hold forth about skin conditions: flaking skin or unguents to heal broken-down sores.

Such uncertainties were, to her, secondary to her apprenticeship and to the practicalities of family life. Her parents had purchased a second business, a grocery shop in the Outer Hebrides and running two businesses in two different locations led to a busy in-between life for the family. Until the business in Glasgow was sold, Sophia, her parents and her brothers moved in ever-changing combinations between these places.

At the finish of her apprenticeship, she was happy to be in one place, and spent a period living in the Hebrides. The apprenticeship which had begun as she explored the boats that took her between Glasgow and the islands was completed. Here she met children and adults with disabilities from birth or from illness. Again

she saw no linkage between herself and the condition with which she lived, and the islanders who had physical and intellectual disabilities. This is hardly surprising, with a concept of disability that largely remained invisible, associated with pity, and not spoken about, to make such a linkage would be unusual indeed. For Sophia, disability remained a state of little relevance

When the plan she and her older brother had to jointly run a fishing boat (he had trained as a Merchant Navy pilot) did not eventuate, Sophia became restless and decided on a change in lifestyle. She moved to England, and worked at various jobs such as ambulance driving, and cooking in a works canteen. She then moved to technical work in factories, applying the engineering skills she had learned in a different setting.

When, in 1958 she met and married her first husband, "good looking, very much a ladies man" (28), her psoriasis was in a relatively quiet state. She had continued to be diffident about close relationships, but found, when she told him that he "didn't seem to mind to the same extent that I minded" (27). This unexpected "tolerance" may have been part of the reason she chose to marry, since distances and differences continued to grow. Sophia and her husband had a son in 1960, and both loved him greatly. But the couple parted after five years of marriage when living together became too difficult.

Sophia had worked while she was pregnant, and again after her son was 6 months old. Her husband earned low wages, and she enjoyed the industrial research work she did, and the independence it gave her. But it was not easy, in social terms as well as in financial terms. She found it was "a very difficult life to be a woman on her own with child. Being a sole parent, a divorced woman, made it difficult for her to enjoy easy social relationships, as her "single" status was seen to be suspect. Sophia found that "you don't make many friends, because if you make friends with a nice couple, you know, your child has made friends and whatnot, the wife is

always suspicious of the unattached woman, so you have to tread very carefully" (29).

The sense of social isolation was difficult, but more unsettling still was the social climate which developed following the war. A cold, paranoid and adversarial relationship grew between Capitalist (western) and Communist (eastern) states, and an arms race began. At the same time as nuclear technology developed into nuclear weapons and nuclear power stations such as Sellafields grew, the horrific effects of atomic warfare and nuclear weapons grew in people's awarenesses. The stockpiles of nuclear weapons caused deep disturbance, and people took part in huge anti-nuclear protests, such as the Aldermarston march. Sophia felt that many teenagers were particularly affected by a general sense of frustration and helplessness. She saw their wild, self-destructive, and violent behaviour reflected a society with little to offer its youth. Many at the time were, she saw, pessimistic about their chances of continued survival.

Although Sophia felt there were advantages to nuclear technology in the power stations or in medicine, she found the atmosphere of suspicion and hate frightening and difficult to live with. Like others, she moved away from proximity to the military bases, out of the firing line. She took her son to the Islands for a while, and rapidly married again. But that was short-lived, and she moved hastily to Glasgow, to hide from the violent and difficult man who was now her husband. She hid there until she was able to arrange to leave for New Zealand, to which first her brother, then her parents had migrated.

Migration was difficult to arrange, as Sophia was, by now, 35. She was also a sole parent. Relatives, chiefly her mother's elderly aunts, paid for her passage out and in 1966 she sailed on a migrant ship, coming through the Suez Canal just after it had reopened. Landing in Auckland, she was warned by her mother that attitudes and meanings were very different, although the language in both countries was

English. Sophia rapidly observed this gulf, and recalls that it was huge. New Zealand attitudes and society were much stranger to her than was the thermal area at Rotorua; a place which so disconcerted her when she and her parents visited en route to Wellington.

She recalls the contrast in relation to shopping: the choice of merchandise to be bought was very small, and how women would still travel to do the shopping wearing hats and gloves. But it was the status of women which she noticed most- "I found they were really trampled on...very discriminated against"(39). She contrasted this with the independence of women in her Scottish upbringing. In Scotland: "It's the wife that rules the roost, even manages the money, yes has the economic power. He hands over the wages...she gives him his pocket money for the week" (39). Women in England had less autonomy than in Scotland, but considerably more than in Aotearoa/New Zealand.

She was particularly annoyed by the position of women in the workforce: that few women were in the workforce, and that those who were in employment did not get equal pay, as her marine engineering employment had led her to expect. Although she passionately supported equal pay, and felt that New Zealand employers were not, in overall terms, good at putting this principle into operation, Sophia's employment in New Zealand was always at rates of equal pay. She was employed as a teacher, where she experienced equal pay, until she retired in 1980.

On her arrival in Aotearoa/New Zealand, she settled near Wellington and moved to employment in teaching. Her transition into teaching was made at a time of teacher shortages, and her technical skills were desirable. From teaching at the Technical Correspondence Institute, she taught at Kapiti College, Hokio Beach School (in a DSW Institution), and at Paraparaumu College. It was enjoyable: "I really loved teaching" (43), and teaching fitted well with the times that she needed

to be available to her son. But an acute bout of psoriatic arthritis in most of her joints meant that she had to take early retirement.

When the flare up first occurred she went to a general practitioner (GP), but the contact was unsatisfactory. He told her it was her imagination and nothing was wrong with her. By the time she was seen by an aware GP, then by a rheumatologist, the episode was beyond control, "it was firmly running through my body like wildfire" (44). All her joints were affected, and she passed the next three years in bed.

By this stage, her son had moved away, and she was at home alone. Home help took some time to be approved by The Department of Social Welfare (DSW), so that her only option was to crawl from bed to the kitchen when she needed to eat. When home help was granted, so were meals on wheels, although by then, the flare up had begun to subside, and more activity slowly became possible. She became involved with trying to extract money from a reluctant DSW, and the dispute proved to be drawn out and difficult to settle.

As Sophia became more mobile, she received a small amount of rehabilitation in the form of hydrotherapy and physiotherapy. The physiotherapist told her of a nascent organisation of disabled people, which became Disabled Persons' Assembly (DPA), and she was keen to become involved. She recalls "there was nobody to plead my cause [with DSW], and that was one of the things that actually got me off my bed. I got so angry. I decided I was going to do something about it"(46).

Her consciousness of disability issues, increased and the lack of personal autonomy grated. When first she went out shopping, after being in bed for two and a half years, the district nurse who visited in her absence wanted to call the police out to break into her house to see if she had collapsed, then "told me I had no right

to go out unless I informed them first" (47). To Sophia that was an illustration of the problems of disability in the early 1980s. She paints a picture in which:

> The health professionals treated you as a sick person and they owned you professionally. You were a number, and they owned you, and they owned your illness or your disability. You couldn't make choices. You couldn't do what you wanted to do.(47).

When DPA held a meeting in 1983 that heralded its beginning, she attended. She became involved at local and national levels.

The next six years saw great developments in relation to disability, and Sophia found her involvement exciting . She particularly remembers the disabled people involved who had "strong senses of social justice and injustice, they had charismatic personalities and they were all round the place" (49) Further, the government started to listen to them, and take them seriously. A particularly celebrated success was the legislative status of NZS 4121, the standard for access to buildings. But she also strongly supported efforts to bring disabled people into the mainstream of community life, in both attitudinal and behavioural change.

Other changes Sophia has been pleased to see include the provision of hearing loops in meetings, to ensuring that information is in a format a blind person can use, to sporting coverage on television and to ensuring that disabled people are not excluded from public appointments or from speaking on their own behalf. She supports independence for disabled people, and indicates a common perception among disabled people of what independence means to them: autonomy, decision-making power, and choices.

There is, however, some blurring of the concept of autonomy for disabled people in her views on psychiatric disability. Sophia believes that there will be an ongoing

need for institutional care for a considerable number of people, whose "behavioural problems" (52) preclude them from living in the community.

> We cannot classify them all as able to live in the wide open spaces. They're too wide, too open. There's not-they haven't got the skills to be able to make the rules for themselves, to be able to live in that. (53)

Autonomy for people with psychiatric disabilities cannot be absolute, she says and their lifestyles and choices are much more bound up in the opinions of others. Sophia sets a decision making process firmly within the wider context of a "caring society of course. A caring society sees somebody needs help and they know where to get the help, and they can talk that person into giving help" (54). Such a caring society does not proceed according to rigid rules, but according to each individual set of circumstances. She sees no contradiction between the two perspectives on autonomy for disabled people.

The years of disability and community health activism came between the end of the first acute episode of psoriatic arthritis, and a second bout which began in 1995, and was still evident by late 1996, when the interviews were taped. During her period of activity she was a member of the Wellington Hospital Board, and was a board member or founder of local community councils and disability trusts. At an individual level she put large amounts of energy into advocating for ordinary disabled people who needed to deal with departments or organisations concerned with health or disability.

The second acute episode of arthritis is set in the context of increasing age, and further limitations to mobility as joints already affected by the first episode are damaged more, and Sophia sees few options to support her, an older woman alone, to remain in the community. Sophia considers the issues of caring relationships, dependency and aging with a disability with a sense of bleak resignation. Caring relationships are, to her, intrusive, exposing unwelcome

complexities. Not only must one face "an invasion of your privacy, because if you've got any personal cares done for you, I mean that is very personal" (56), but also one must " face up that you can't do certain things, and that they've got to be done for you" (56). Through her experience of such matters, Sophia has become aware of the ongoing dangers -resentment that increasing limitations mean changes and extra complications, and the "very grave danger of completely collapsing and letting them do everything (56).

Such dangers highlight the intricacies of what caring and dependency actually mean in Sophia's life. In caring, trust is central to how she manages and maintains the caring relationships she must enter into. She describes the fear that results when trust of a carer is not present: "what the heck am I going to ask them to give me for my meals? They don't listen and they do things the wrong way. They're too rough, they don't know how to..." (57). Such lack of trust can mean not asking the carer to undertake necessary tasks and enduring pain as a result. The trust is not only in a carer's ability to perform tasks, but equally in the ability to listen to what they are told, or to follow directions. It is through this second aspect of caring that Sophia can remains in charge of the process, and thus of her autonomy. The third aspect of a caring relationship that Sophia values is reciprocity, a "two way experience, and you can't expect the impossible from your carer...that's something that has to build up over time". (58)

Sophia is concerned about paid care. The state-provided carer services she uses are have tight criteria for eligibility, and the care worker is responsible to the employing agency, who is, in turn, accountable to the funding agency, ultimately to the government. Thus care recipients have little real power over the terms on which they receive care.

The consequence of these relations of power is that Sophia hesitates to complain or to ask for changes of carers. She says "you tell the organisation 'please get me

a different carer, I just can't get on with this one'. But then you're a bit scared to complain because the usual retort is 'oh everyone else finds them very good'" (58). The upshot is "you don't really like to complain because you feel you're going to be victimised" (59). She is further concerned about the low standards for this kind of work, with pay so low that people who are doing this work because "it's the only way they can earn some money...there are very few that are dedicated in the actual job" (59).

In delineating what goes into caring, Sophia is clear about the boundaries of a caring relationship. As well as the paid carer relationship, she describes other relationships in which disabled people care for one another. She gives the example of her caring relationship with another disabled friend in which option generating, information, practical suggestions, advocacy or the act of listening may all be components.

But her understanding of a caring relationship goes beyond a role reversal where disabled people can and do perform conventional 'caring for' roles. For Sophia, such a conventional relationship, with different faces (disabled people), but unchanged roles (one person actively 'cares for' the other who solely receives care), is unsatisfactory, and only partial. Her relationship with the other disabled friend may involve her in giving, but equally she receives, for example practical assistance, shopping, listening or visiting. It is the balance, the ability of both parties to give and to receive that which the other requires and values. Such a conception of a caring relationship is far beyond what is usually portrayed in much of the literature on caring.

She positively values what disabled people can do for one another in a caring relationship where "its the sharing rather than the saying and doing, I think...and even you can share in the silence, you don't need to say anything" (67). The support which a disabled person gives is based on a shared experience:

It's there, and that support you're getting, which you don't get from an able-bodied person, because they don't know what you're going through...with a person with a disability, you don't need to say that. You're already sharing. (67)

Sophia's inclusive concept of caring relationships stands beside, and in contrast to her everyday realities. She lives alone at home, and needs to use state-provided non disabled carers for many of her day-to-day requirements coming into the home. It is a life of increasing difficulty. She is very aware that the episodes of arthritis has affected most of the joints in the body, and that options for both 'treatment' and 'care' are few- "which is pretty devastating" (61). She insists though, that a home lifestyle, rather than an institution-hospital or rest home is necessary:

Take me out of my home and I'd be lost and devastated. I couldn't cope outside my own home. I mean, I have had a couple of spells in hospital, and one was a month long, and I was under stress all the time I was there. (61)

Sophia experienced the processes of assessment for eligibility for disability-based benefits during her first episode of psoriasis. During the most recent episode, she was re-assessed according to the processes deemed suitable for older people. Sophia reacted indignantly to this. With disability based assessments she experienced a loss of autonomy, but she found an age based assessment process worse. She describes the process as one where:

You're looked upon as somebody who has reached a certain age, and you get the strong feeling that the professionals want to take control over you, and organise your life for you, and talk about how when you can't live in your house any longer you must start thinking about what resthome you want to go into, and you'd better start making arrangements to do this and that. It means the end of the line, and the next thing is the box, and the six feet under. (63)

Sophia sees this as a labelling process, and declares

> [For] the person with a disability to move into the elderly group, we still regard ourselves, because we haven't changed as a person with a disability....Oh sure, we may be getting older, but why should we have a label put on us...why take that one off and put another one on, or even worse, just stick another label on top of our old label, and it disappears, and now we're told 'oh nothing wrong with you except age'. (64)

Postscript

Sophia's health did not improve. She went into hospital early in 1997, and died there in September 1997.

OLIVE BROWN

When she reached adolescence, Olive made contact with a new and vital cooperative and open-air movement called Woodcraft. It proved to be a decisive life-long influence: on politics, social life, work and marriage. At the beginning, it was a useful means for dealing with difficulties at home. Later, Olive would use its principles of self reliance, and cooperation to redesign work to fit her in greatly altered circumstances.

The First World War had a huge and ongoing effect on Olive's parents. Her father returned from the war in a state of total depression and nervous exhaustion. He spent the next 10 years in a home for returned servicemen, and a marriage to her mother was delayed until he came out from the home. Neither nerves nor health ever recovered fully though, and his disposition was always uncertain.

Olive was born in 1933 into a working class North London household still in the grips of a depression. Employment was not easy to come by, and Olive's father remained too fragile for anything other than part-time work, usually of a temporary nature, such as selling insurance. From time to time her mother had "the occasional very rare chance of scrubbing the church floor, for which she earned a few pence" (70).

The war had brought disability and poverty to other soldiers too. Once, when Olive and her family were waiting to see a Christmas pantomime, they encountered a group of 4-5 disabled ex-servicemen busking for money. But on the whole disabled people were not visible, and "I can't remember anybody talking about it...I certainly can't remember any concentration upon, or mention of, or sight of disability" (17).

Olive's mother was of an optimistic and loving disposition. She rode through the outbursts of temper to which her husband was prone, such as throwing the dinner

at the wall for no apparent reason. Her equanimity was such that "although obviously all of this was very very upsetting, it took nothing for her to come alive again" (2).

While the loving warmth of Olive's mother made her life easier, she found that her father's temperament was more influential and less useful. He was very fearful of what could happen to Olive "a lot of built-in fear that harm could come to you very easily". Thus there was no bicycle, or going swimming with friends" (2).

Olive also had a squint in one eye, which meant she had to wear unattractive patched-lens glasses. When this was set alongside a fearful and uncertain home atmosphere, which she later considered was not "a good atmosphere to grow up in really" (2), the consequence was "probably a very introverted and lonely kid" (2), who immersed herself in books, card games and puzzles. Olive's younger brother was not affected by her father's temper to such an extent. Instead of fear, he was encouraged into sporting pursuits and "I don't think he ever noticed some of the things about my father that I experienced" (7).

Air raids coincided with the beginning of her schooling, and meant a period of schooling held in somebody's front room. However it did not mean a complete disruption, and when a new school was built near her home, Olive continued to build a good schooling record, passing the national exams at 11 with a scholarship to a local "all girls, very academic" (3) grammar school.

Few of the other pupils at Enfield County School came from a working class background and this was very noticeable at the end of the day, when middle and working class girls went home in opposite directions. The school's sights were firmly set on academic achievement for all of its pupils "The school was there to send you to university" (3). However Olive realised that no purpose of this goal

was readily apparent: "I'm not really sure what you would actually <u>do</u> with your university education; nobody ever discussed it with you" (3).

As well as the contrast between home and school life, where she became conscious of leading a double life really, both home and school were different to the Woodcraft movement she had become involved with. As she was starting grammar school, World War 2 ended, resulting in many street parties. Adolescents from the street formed into a group that did things together, including a 'youth club' night. Olive's somewhat reluctant father allowed her to go, and there she learned about Woodcraft.

Olive found out how Woodcraft was begun by 19 year old Leslie Hall in the late 1920s. It was a non-religious, non-political organisation for young working class people, run by young people. It had a cooperative basis, a strong sense of community, was given to healthy outdoor pursuits, and pursued equal participation of the sexes. Its philosophy was socialist, and it later spread throughout much of Europe. She found both philosophy and activities very congenial, and through her teenage years, joined enthusiastically in all of its activities, such as weekend camps, folk dancing or concerts. Without the outlet it provided, in what was effectively voluntary youth work, "I'm not really quite sure where the lonely introverted kid would have ended up otherwise...I dread to think" (12).

Although Woodcraft was not political, its orientation was more towards socialism. Thus it gave her the means to form an alternative analysis of the policies and practices of the Tory[62] government. She joined, from time to time, in the peace marches such as Aldermarston. Protest was not, at that time, common: it was an era in which suspicion and conformity were rife, and the suspicion was of anything that seemed unorthodox: "McCarthyism[63] was rife" (5). Such was its level that,

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[62] Conservative

[63] Joseph McCarthy was an American senator whose hatred of Communism sparked persecution of many people whose opinions were unorthodox or too liberal.

when she was 17, and had begun a local Woodcraft group, some parents would not allow their children to attend: "we were accused of being Communists" (5)..

There were three major influences in her life: Woodcraft philosophy, middle-class academic prospects and a very conventional working class home life They did not sit easily with one another, but it was financial rather than any other considerations which finished Olive's schooling at the end of her 5th form year. She had very good results in her matriculation exams, but her parents had no money to spare for her education. She recognised her circumstances allowed few choices. Thus "it made sense to start work really" (7).

When she looked to choose a job, Olive found few options. Young women could be shop assistants, factory workers, teachers, nurses or office workers, it seemed. She decided on this last option, and obtained a position with the Bank of England. Even this was not a straightforward process, as not only were good matriculation marks required, but also they had to be gained at a particular (superior) kind of school. After Olive got there, she found that all the fuss was not because the job was complex, since "anyone could have done it really" (8), but "it was purely their standard" (8).

The work was boring: elaborate routines and complex hierarchies abounded, with work to be performed in a properly dutiful way. Olive was given the task of counting bundles of 5000 one pound notes to which 75 minutes per bundle was allotted. When "It was noticed that I wasn't counting my notes properly...I was quickly despatched to a different office altogether. I couldn't be trusted to count my notes properly" (10).

There was another defect, Olive found: men and women were paid differently. She was aware that in the 1950s, women most often earned less than men; In the Bank of England, "I would hazard a guess that women might have earned about a third

of what the men were earning" (10). Olive saw how men were paid substantially more for performing the same tasks as women. Further, women would not be promoted to senior positions that men could obtain. At the time, this was accepted with little dissent as normal practice. Further "you didn't play around with jobs in those days" (10), and the job offered lifetime security, low interest mortgages, good welfare services to employees and a good pension at the end of a lifetime's service.

To Olive "everyone was involved in sex role discrimination at that time. Most employers were....It wasn't even an issue" (11). So the discrimination, apparent in many aspects of social life, was simply not an issue. "I mean we might have laughed about it, or joked in the Bank that we knew we did far more than the males...But it was the way things were" (11). Rather, she chose to focus on her Woodcraft-related activities. Because the Bank of England had a large and elaborate staffing structure, people who were employed could legitimately be in many different places. Further, she could use a degree of 'flexi time'. When tasks were completed before the allotted time, the extra time available could be used on non-work activities. It meant Olive could, legitimately, be in a different place, and use flexi-time to buy folk-dance records for her Woodcraft group.

Woodcraft provided a further focus: she met and married a fellow Woodcrafter who was employed as a tradesman in the electrical industry in 1953. They shared many hours in Woodcraft activities both before and after marriage. Finding accommodation was difficult, and by 1956, the year her mother died of cancer, they had bought a first house: a considerable achievement for a working class couple.

They did not rush into having children however as "I've never seen any need to rush into it" (18) although "it was the expectation in those days" (18). Shared values and outlook, along with an enjoyment of each other's company meant they

were comfortable to wait before having children. So in those years, before children she and her husband explored the things that had caught their imagination: she learned to ride a horse and to ski. They went on camping holidays in Europe.

When she was 30, she finally decided that she no longer wished to work at the Bank of England. She went to work in a local library, enjoying the more relaxed lifestyle. A year later, in 1964, she had her first son. It was at this time when she became concerned that living in London had become too difficult, congestion made movement impossible, and there was a sense of gratuitous violence in the schools. They decided to move to a more rural setting, and found a house in a small settlement in Cornwall.

Their time there was happy. She, who "had always expected babies to be hard work" found satisfaction in her son and daughter, who arrived in 1967. She had been involved with playgroup activities. A chance remark in this setting set off thoughts of Woodcraft, and, with a small group of like minded souls, she established Woodcraft in the town.

For two "wonderful years", (23) they ran a very busy schedule of Woodcraft activities, but the uncomfortable lifestyle that had caused them to leave London gradually made its way to Cornwall. Changes to work practices in her husband's occupation increased the risk of physical harm. Neighbours who taught nearby returned with tales of violence in schools: "razor blades embedded in the sand, broken glass scattered in the sand in the jumping pit" (24). The motorways, and crowding were scheduled to reach their home so that "sleepy Tavistock was going to become just like the place we had left behind" (24). Olive was very uneasy and, with her husband of similar mind, they decided to move. They wanted to move well away from the unrest and crowds-things they did not want to be part of- and settled on New Zealand. The decision made, it "suddenly became the next adventure" (25), and they promptly emigrated in 1972.

Although not their original choice, they settled in Christchurch, and both found employment similar to what they had done in England. They wanted to make their savings last and had become rapidly aware that, apart from basic foodstuffs, living here was very expensive. They settled into an easy routine, but 14 months after their arrival, and six months before the beginning of accident compensation (commonly known as ACC), Olive fell and dislocated her neck.

Olive went to the Spinal Unit, which was, at the time, located in cramped conditions at Christchurch Hospital. For an woman with a family and an active lifestyle, life changed dramatically. Because the injury was high on her spinal cord, she lost most of her movement, and required a high level of personal care to undertake most of the activities of daily living. She ended by living permanently in an institutional setting; a private religious hospital. It was a decision born of necessity. Prior to ACC, there was no publicly-funded assistance for the necessary help in a community setting. Olive did not believe that her husband should have to take on the task of full time unpaid carer, and thus the decision was, in effect, made for her.

Olive's family adapted well to a changed situation. Her husband continued to work and to function as a sole caregiver to two school-age children. The children developed extra self-reliance. Olive went home at weekends, and, somewhat to her surprise, continued to be a parent. Reflecting on what being a parent with disabilities, she discovered that the work did not begin and end at doing 'things'.

> With regard to the cooking and the clean clothes, and all the rest of it, it didn't matter two hoots. It doesn't have to be you at all!...what you are needed for, I believe are the intangibles...It's not what we do or what we say, but it's, just maybe, the people that we are. We convey values, we can give confidence, we can give self esteem. Its all those things that I think we are important for. (30)

Olive's daughter was widely acclaimed by acquaintances as independent and popular. Her son was academically gifted, and received much praise. Olive published articles and took part in some radio programmes. It was then that she realised "that role [caregiving] is just totally unappreciated, whoever's doing it" (32).

Olive and her husband had always operated their marriage with an assumption of equality that translated into equal participation. Tending to small children at night was something done by both parties. Similarly household tasks and decisions were shared. Thus her reflections on the 'coordinating carer' role were more on how it about how the role did not acknowledge whoever undertook the role, rather than impact of the role on women per se.

While intrafamily relationships appeared to undergo very little change, the situation was very different with almost everybody else. Olive found "where there was a difference as far as I was concerned was in the way I was treated as a person, and that was probably the biggest shock I will ever have in my life...It meant that I was a thing and not a person" (33). She saw, starkly, that issues of power and control were central. She contrasts the usual pattern where we usually treat other humans with respect and the assumption of equality with her situation of changed capacity where

> What I found was the loss of my ability took away my equality, and I couldn't understand it because the voice from inside me is 'Hang on, I haven't changed. Sure I can't move, but I'm still me'. (34)

This, she saw was further exacerbated by assumptions related to a medical perspective. There were assumptions, both overly optimistic and overly pessimistic about what she could or could not do, based on the medical description of her

injury. Medical professionals told her that she "should be able to undertake various activities, such as feeding herself because her injury was at a given level. (38).

From the start, when she struggled to assert her autonomy, her humanity, Olive became labelled as a troublemaker. However the struggle became, she found, more and more effective as time passed: "it has been a long hard fight, and it still goes on. It goes on today where I do it with more certainty and more confidence, because of the few battles that you do win along the way" (35)

The battles included the highly authoritarian, and medicalised regime at the private hospital where she resided. Olive was "a thorn in the flesh of authoritarianism" (40), and concerns were expressed for her mental health, because of her 'negative' attitudes. When she heard of attempts to move her into Sunnyside [Psychiatric] Hospital, apparently because she was 'bolshy', she took legal advice and when the next attempt to coerce her came she told them "anything you choose to do...if it's without my consent, it constitutes assault and I shall sue you." (41)

After a year of exhortations by the authorities at the hospital to 'progress', Olive decided to undertake extramural studies at Massey. It was designed "to get the medical hierarchy and the nursing staff off my back" (39), and to stimulate her mind which, she felt, would respond in a more satisfactory nature than her body. She enrolled for two papers. Ill health during 1975 obliged her to drop one paper, but in 1976 she completed another two papers.

Satisfied that she was able to achieve some of her goals, and to think at an advanced level, Olive then turned her attention to other work-associated avenues. She had begun to develop a perspective on the relationship between disability and employment, along with the changes she felt were necessary. In 1976 she broadcast this analysis.

Other avenues of work opened in the years that followed. They arose because "it was the common sense of the situation: you <u>knew</u> what you needed and what you could <u>do</u>" (43). Olive became involved with a voluntary organisation called Bridging New Zealand, which was set up to give young New Zealanders time working in a kibbutz. She organised a number of fund raising events for the trust. She undertook tutoring for remedial reading at a local high school. During the International Year of Disabled Persons, she went into schools to conduct disability awareness sessions. She was part of setting up a tape library by and for disabled people. She was part of a community development programme for high school leavers.

All of these activities were in addition to her parenting, and all were unpaid. Olive is clear that unpaid work is "absolutely real." (47). She further reflects on the relationship of unpaid to paid work, giving the higher value to unpaid work.

> When I look back, my most real work has been done in a voluntary capacity...You do whatever you have to do to earn money in order to do the work that you really <u>want</u> to do...work is basically what you're here for, and what gives <u>any</u> of us satisfaction in life. (47)

This is consistent with the thoughts Olive articulated in her 1976 broadcast, and subsequently put into written form (see Brown, 1985). She pointed to the most important requirement for disabled people participating in paid work on equal terms with non disabled people: "we need flexibility. We need to be able to work at the times when we've got the energy to work...we need work to come to us" (43).

She was equally clear on the contribution her unpaid work made. For a number of years she argued successfully to the Minister of Social Welfare that by the use of one allowance for purposes that were not within the strict letter of the regulations, she could contribute unpaid work to many times its value: "could they please

redirect this $10 into petrol money for me to go and give them probably about $70 worth of voluntary work a week" [remedial reading in secondary schools] (47). The work was unpaid but not valueless.

Around 1984, Olive's son had begun university study, and a remark of his challenged her to redevelop her critical thinking capabilities. She realised "like the rest of my generation, I'm saying yes and no in the right places, and that's about it" (49). At 49 she decided to study at Canterbury University and she took up political science and education. She experienced a smooth passage through both departments, and found her requests were answered. She emerged with a Batchelor of Arts degree, but decided not to proceed with post graduate studies: "I felt like getting off the roundabout for a wee while. Also, as I said, pieces of paper, unless they're for a purpose, don't really have much meaning for me" (51).

But Olive had enjoyed the atmosphere of university life, and when she indicated her willingness to help to organise research materials, political science promptly enlisted her to perform tutoring. This situation, which has lasted over 10 years, "only came about through voluntary...my employment in the real world of today has come about because of voluntary work" (53).

When the children were late teenagers, she and her husband parted amicably. Relationships between the two remain friendly and respectful as they pursue their respective lives.

Over 23 years have passed since Olive's Spinal Cord Injury (SCI), and she finds that she focuses less rather than more on her bodily maintenance. She points to early lessons from the Spinal Unit, with its focus on her bodily limitations: lung delicacy, skin vulnerability, susceptibility to urinary infections and bowel regularity. With all these concerns "if you're not careful you can come out as a hypochondriac" (56). Rather she found that she became familiar with what her

body needed for maintenance, since others, "don't actually know" (57). In this initial phase of SCI, the medicalised perspectives on her disability were dominant, but such an understanding has been succeeded by a realisation that disability is a problem (not a medical emergency), and can be competently managed by the individual concerned in the way they choose.

Olive has thought little about ageing. Although she does not necessarily regard it in a negative light, she does not regard it as part of her life, and quite distinct from disability. Her concept of ageing has always been that it is largely attitudinal, where "you could be talking to someone who has never been young in the way they think or whatever...I don't honestly think age matters from its own point of view" (59). She does not believe that age and disability are interrelated: "I've always thought in this situation that age is one thing and disability is another. Put the two together, and thanks but no thanks" (59).

She further distinguishes between age and a state of dependency, often arising with age. Olive points out that this dependency more frequently arises when too few people are attempting to respond to the needs of too many others. This is a situation that she has seen arise in her own hospital in response to changes to the economic climate and to employment law. She describes a constant stream of part-time carers, and numbers of carers that are too small to provide adequate care to people with whom they work. Such a situation enforces dependency and as Olive sees this encroaching on disability, "if the caring situation...is going to deteriorate, then I can't answer for what I'll be like on the receiving end"(60).

Olive highlights a further advantage to ageing: because there are fewer demands, than in youth, such as in building partnerships, beginning financial security, parenting or starting careers, age means less 'clutter'. She sees this in her tutoring where "I know what I'm doing... I feel more confident and I think it's because we've got time for them" [the students] (62).

When Olive reviews the way in which she (and her mother) has experienced work, there are two points of contrast. First are gender issues: the differences in wages and status between men and women which have been such an ongoing feature. From her mother's occasional paid domestic work to Olive's own paid work, pay was never equal between men and women, and men were always in charge. At the time, she took the differences completely for granted: "it's the way things were" (70).

Olive would not, at this point, consider the situation acceptable. She says that pay inequality for the same job is no longer accepted: Yet she still sees a gender gap in earnings, since:

> The situation is with a lot of women out there, who are doing incredibly hard work for peanuts...it is work that very few people would want to do...unless for the money. The pay is terrible. (70)

Second are the disabled-non disabled gaps. Olive has long espoused the need for work to be more flexible in its practice, so that people with disabilities can participate in ways that respond to their needs. She points out that when flexibility is not present, it hinders people with disabilities from participating in either paid or unpaid work.

Olive's future residential and care options are uncertain: the hospital where she has lived since 1973 is scheduled to close, and community living alternatives are not settled. Yet Olive feels involved in a lot of disability issues and is positive: "I feel that really the institution matters little....I feel like I'm part of whatever's going on at the moment" (71). And elaborating on living positively: "I've come to the conclusion that to have a satisfying life, concentrate on something and do it as well as you can" (74).

VERONA MOYNIHAN

There has been a lifetime of caring for others and involvement in her surrounding community in Verona's life. Close family links, and a secure, lifelong spiritual involvement have been important bases to this involvement. A crowded study is testimony to her ongoing work, and her contentment suggests that Verona has found great satisfaction from this work with others.

Verona was born the third of her mother's six children in 1932. The tiny settlement of Hoe-o-Tainui was in the area where both her parents grew up: rural and isolated. Verona's father came from rural English immigrant stock. The family was large, working class and also ran small holding. Her father was a labourer. Verona remembers a very patient man who worked long hours, and "you never ever got a bad temper out of him, or anything like that" (3).

His equanimity was necessary when Verona's mother, a bright, happy child of North Italian immigrants died of cancer in 1939, when she was 33. Until just before she died, Verona's mother stayed in the family home at Otarahaunga. Her children were between 9 and 3, and they largely looked after their mother while their father was at work. Verona "can remember dad going off to work, and giving us one pill and telling us that when the clock hands were at a certain time, we could take that pill in and give it to her" (3).

During this difficult passage, the children had cared for one another. Older children got younger children up and dressed. After the death, Verona's father returned to his job driving a bulldozer for the borough council in Otarahaunga. But the living situation for his children needed greater systematisation, especially since World War Two had begun. They went to live at the small farmlet run by Verona's grandmother at the foot of Taupiri mountain. It was the refuge of most of

the children from her father's family: most of his brothers and cousins had gone into the army, and the women joined together to look after children and farm.

During the war years, Verona's father was in the army camp at Ngauruawahia. Although he was relatively close by, they saw him little; the main contact was by letters. But in the year before he went to the camp, he was still bulldozer driving, and only came to the farm to see his children during the weekend.

War seemed a rather distant matter to the children. Their grandmother was a warm woman with "a beautiful Irish voice" (5). The children "always got out on the front lawn and waved to all the troops as they went past" (5) on the 6 o'clock troop train. There was little of the level of public communication about national events that is present today, and the daily troop train comprises a large part of Verona's memory of the war years.

There was one other war time memory, of practice air raid drills at school. When the siren sounded, the children raced into air raid trenches in the playground. This exercise had a certain dreamy quality. Verona found "it became a sort of a game, rather than that war was coming" (5).

School too had a distinctive feel to it. Of particular note were the standard six boys. They were farmers sons who were "strapping young men" (6), and had taken longer than usual to get to standard six. Verona was impressionable, and was struck by the "big hairy legs" (6) of these 'schoolboys'.

There were no male teachers, except the headmaster, and two groups of older and younger pupils were taught in the same room at the same time. Verona's teacher was a woman given to regular physical discipline: strappings and blows with the ruler were freely used. Her uncertain temper was distributed freely to most of the

class, who regarded her with terror. But since Verona overtook her older sister, the teaching methods may have been effective to some extent.

Verona loved to run, and in 1941, she ran to fulfil a school errand at morning break. As she did so, she tripped and skinned her knee in some sand. By lunchtime she had become rigid, and could not get out of her desk to go home to lunch. After her desk had been partially dismantled to get her out, her brother and sister carried her home. There, her worried grandmother found she was ill and put her to bed. They had no transport until her father arrived home two days later. He then took her to the doctor in Ngauruawahia, and the doctor "looked up, saw me, and without examining me said 'Waikato Hospital quick'" (9). Another rapid trip took her to the children's ward at Waikato Hospital, where she was to spend the next five years.

The osteomyelitis which had set in from Verona's injury to her knee was, the doctors said severe. She later found that she had contracted a rapid acting form of the illness At the time, penicillin was not generally available, and the infection that set in was severe and widespread. She continued to be ill and in great pain: "for the next five years I was in and out of consciousness all the time" (10).

The form of osteomyelitis Verona had was said to be of rapid onset. Her father was told that "normally children who got it would be dead within 24 hours of getting it. Verona was of a robust constitution: "they reckoned I wouldn't lie down and die" (both 11). Various treatments were tried, but did not succeed. There was plaster, weighted splints and physiotherapy. There were also painful sessions involving sulphur and bluestone to burn down the raw parts of the wound, which was then packed with rolls of dressing to enable drainage of infected matter. Very little seemed to work, and she continued to be very ill.

When she was 12, Verona was given the last rites as "I was at a stage where death was imminent" (11). At this point, a new surgeon proposed that they amputate her legs, in order to save her life; they would cut a lot of the poisoning out:

> He [the surgeon] said 'I'd like to amputate'. My father said 'no', and then the little nurse sitting beside him said 'it will save her life'. So he decided to agree to the operation. They took one leg off, and the improvement in me was so great that within a week they'd taken the other off. (11)

Verona's reaction to the limb amputations was of relief. When the ward's sister came to tell her she had lost both legs, Verona responded "Oh great, no more pain" (21). But she had a continued sensation that her limbs were present, and derived considerable satisfaction when the nurses rubbed the toes on her (non existent) legs, to relieve the itching she felt. The sensation that her legs are present has recurred at intervals throughout her life, but infrequently.

Rationing both during the war restricted travel. Further, it was uncommon for women to drive, and Verona's grandfather was too old to drive so that she could be visited by her family. Bus services were minimal. This meant that family contact, while she was in hospital, was extremely limited. Her grandmother missed her, but could not visit. She was "virtually adopted by strangers in the hospital" (12), and made a number of good friends among hospital staff, families of other, closer living patients, and airforce personnel.

Among other constant influences during her hospital years were the priests and nuns from the local parish. She was able to take her first communion at 13, and the regular visits from clergy continued.

When Verona left the hospital she was 14, and she returned to very different circumstances. She now had a stepmother as her father had remarried the

previous year. Her stepmother had begun to have children, and didn't understand about Verona's disability. She was to go to a new school where she had to make new friends, and she had at first, no way to get around independently.

Her father was the person who most often carried Verona from place to place. Her sister took her to and from the school bus, which came to the end of their long drive. She participated fully at Te Hoe school for another year. Her teacher was a man who loved to teach: "he could coax anything out of any child" (15), and he ensured that Verona was involved in all the activities. It was therefore a happy year, though her schooling had been badly set back by the years in hospital.

Although the process of carrying Verona around was not financially expensive, it had other limitations. Realising this, local farmers clubbed together to buy Verona a chair-"a big sort of chair with long feet rests on it, and a lean back" (14). There was less need to carry her around, and greater independence for her. But the chair was irresistible to all of the children around, family and schoolmates. They were keen to wheel the new chair around, and such was their enthusiasm that Verona was tipped out several times as they learned to 'drive'.

While the chair brought more independence for Verona, there were still problems. In a country district, a lot of activities or facilities were reached only by large muddy fields or long rutted tracks. Wheelchairs do not negotiate such obstacles easily, and Verona got used to scooting around on ground that was often muddy or wet. But it also meant that facilities often got less use than was needed, and this was the beginning of a pattern that later meant urinary tract problems.

When Verona went to Te Hoe school, it was a new experience for all concerned. She was very scared, and was again struck by "these big boys that looked like men" (10): the boys she had encountered in hospital were children. Her classmates had never seen her before, and had not encountered a child with no

legs. Verona may well have been the first disabled child they had encountered in an open setting. At the time "children with disabilities weren't seen. They were usually in the back bedroom" (16). But all parties got on well. Even the big boys who had scared her at first were "very nice lads and I got on well with them" (10)

She became a client of the Crippled Children's Society, now called CCS, towards the end of her stay at Waikato Hospital. The visits of their social worker to her family's farm were infrequent, but after she had finished at Te Hoe School, they sent her to the limb factory in Auckland. There she had artificial legs made for her, and she learned to walk with them. Their influence in Verona's life now became large.

From when she was been small, Verona had wanted to be a nurse, with a passionate intensity. But now another course was decided for her by the people in charge at the Crippled Children's Society:

> They decided that the best job for a disabled person would be a shorthand typist...I didn't have any choice really, that was what they thought was right...perhaps they were wiser than what I was, but it wasn't my first choice of what I'd like to do. I wanted to be a children's nurse, where I was looking after small children. (17)

They organised her move to Hamilton and board there with a widow. They also arranged that she attend Brain's College For Young Ladies, which was a private establishment teaching commercial subjects, mostly to the daughters of wealthy farmers.

The establishment was at the top of a very steep rise, and the taxi could go no further than its base. To get in she had to climb a steep flight of steps on her newly acquired artificial legs. They were not always stable, and it took considerable energy to get up and down to the college without falling over. More flights of steps to the toilets were a hassle Verona usually avoided.

Verona took to the commercial subjects taught at the college with considerable aptitude. She was allowed to use one of the new typewriters that had been bought; "because I was a good typist and because I didn't wreck them" (18). She emerged from the year there with good skills, and moved to the Crippled Children's Society as an office worker.

When she went to work with CCS, Verona also acquired a new, more modern wheelchair. It was a more effective mobility aid for her. Although she had artificial legs, she was falling over a lot while using them. The situation was "pretty horrible really, because you never knew you were going to stand up, or whether you're going to break your neck falling over" (20). In addition, the underarm crutches which were necessary started to paralyse her arms. The organisation had, somewhat reluctantly, to defer to practicalities and acknowledge that a chair worked best for Verona.

The wheelchair was not yet ideally suited to Verona's needs, although it was of more modern design, and was collapsible. The footrests, which were not necessary kept catching in the spokes of the wheel, and acting as a brake. It caused Verona to tumble out of the chair, and was a trigger for her to begin to assert that she knew best what she needed in a wheelchair.

Although the Crippled Children's Society seemed to have some ideas about how a disabled person ought to be and what should be good for them, Verona saw matters differently: "I never let my disability stand in the way of what I do. If I wanted to do something, I'd do it. In the rural setting, she joined her brothers and sisters in handmilking. Because she cut thistles down to feed to the cows, they became used to her being in the paddocks with them.

A sense of being a young woman came late to Verona. She had come out of hospital "as a very tiny immature girl...I probably looked about 6 or 7...people tended to treat me as a little child" (24). By the time she was 18, she felt she was growing up, and enjoying life.

In 1954, years of difficulties with her kidneys came to a climax. One kidney, which had been 'bad' for years before this stopped functioning. Verona needed to have it removed. Years of being unable to access toilet facilities finally took their toll, but hospital staff were impressed that it had taken so long to reach this point.

Life in Hamilton continued in an even pattern after this. Then, later in 1955, Verona met the man she was to marry. This occurred through the agency of her local church: she was "on his list" (24) to have transport provided to church services. They were both from families steeped in Catholicism. She had absorbed the practice of her faith in an effortless manner. For both the daily religious observances were natural. The courtship proceeded in the conventional pathways of the time: local dances, cinema visits, church groups with friends who did not suspect anything. When the situation became 'serious', visits to meet the respective parents followed.

Neither saw any reason why they would not pursue a conventional marriage, including the children that both wanted. Verona had visited a doctor, who advised against having children because of the combination of disability and having only one kidney. Forty years ago, obstetric practices were less sophisticated, and the risk of infant or maternal mortality was higher. Thus "having a child wasn't to be taken lightly" (33). It seemed to Verona that her disability was more important. The common belief was that "disabled people didn't marry, didn't have children-it was probably a no no" (33). But she wanted to have children, her fiancee supported her decision and she disregarded the warnings.

But her fiancee's mother was unhappy with her eldest son's intentions. She "didn't think it was right...her reasoning was that I couldn't give him any children, and she wanted grandchildren" (27). The parish priest was their ally in the ensuing differences. They married, but matters were difficult at the start. After the wedding they decided to move to Invercargill to live to "start on our own, and do our own thing without the interference of the family" (27)

The children who were so important to Verona's mother in law were also important to Verona and her husband. Her first pregnancy proceeded extremely well. When she went into labour however, difficulties developed because the baby was large and her pelvis was small; "they kept on saying he was too big a baby for me" (28). This was not necessarily a problem but at the time" they had a theory that first babies were never taken by caesarean section; that first babies should be natural" (28).

Verona was in a difficult labour for 19 hours before they called a specialist to deliver the baby. They then took her to the theatre to remove the afterbirth. The baby was alive at birth, but died shortly after. It had been estimated that the baby was large when she was X rayed at six months, so Verona was disappointed that this knowledge was not used when it came to the birth as she had keenly desired the child: "we had no reason to believe there would be anything going wrong, and so to go into labour and thinking you're going to have a live child was pretty tragic" (31-2)

Immediately after the birth Verona was "devastated, just devastated" (31), and this grief was made worse when she was put into a main ward after the birth, so that she had no privacy in which to grieve. She further encountered women who had given birth to children who were not wanted, and the contrast was, to her, almost unbearable.

Verona again became pregnant and had three further sons after further uneventful pregnancies and trauma-free deliveries. Her husband was as pleased as she, both came from large families and enjoyed children.

Verona was again brought into contact with rigid expectations of how birth and mothering 'should' be when her last son was delivered by caesarean section. The specialist at the time thought she should not breastfeed, as she had done for her other sons, because it would take too much out of her. When he decreed that she would not breastfeed, Verona again listened to her own inclinations, and her husband again supported her decision.

During the time her children were growing up, Verona cared for many others in addition to her immediate family. The first additions came when her oldest son was three weeks old. Then she responded to an appeal from her parish church and took in a family of 8 refugees from the Hungarian uprising. They were with Verona for three or four months.

Because the family home was large, and there were many playthings for children, Verona soon found many neighbourhood children would come to their house. They were "there from eight o'clock in the morning until five o'clock at night" (36). In addition, she fostered children, both short and long term for the Presbyterian church, and for the Department of Social Welfare. Numbers of the children were disabled, some severely so. At times she provided respite care for disabled adults too.

Verona's response to these additions to her 'core' family was unequivocal "it was great" (37). Her husband was "very keen, he liked me to have them" (37), and her sons also "enjoyed them" (37). Her middle son was particularly happy with the additional children, and that has continued into adulthood: in addition to his birth children, he enjoys close contact with all the neighbourhood children. Years later,

children Verona had fostered would greet her warmly and remember a good period in their lives.

When she was almost 40, Verona was recruited by the local Paraplegic Society's president to join their sports team. His method of recruitment was simple: she was telephoned to say "you're in the team" (40): Verona protested that she knew nothing about track and field sports, but she was given a crash course in throwing javelin and putting shot. After a fortnight of training she went to the national games and gained five gold medals.

Concurrently she became the secretary of the local country and western club, the Paraplegic and Physically Disabled Association, and Riding for Disabled. Her children were teenagers and she was still fostering other children. When an acquaintance at the local hospital offered Verona paid work in the office of a sheltered workshop," I wasn't sort of keen" (41). However the manager persuaded her to take up the position, and she began the next week.

For the following two years Verona ran a busy office, undertaking a large range of duties. But she was deeply offended when she found that the woman who had performed the same job before her had been paid $4.00 an hour while she was only paid $2.50 an hour: Verona took home less than $100 for a forty hour working week. The main reason for this difference was that she was disabled. She protested repeatedly, but "every time I mentioned it, there was always some excuse for not being able to do it" (42). She was especially annoyed that "they were recording that I was a client, rather than the personal secretary of the manager" (43). And her paid work was still in addition to all the unpaid work she had already been undertaking.

In 1982, when her sons had all grown up, Verona and her husband moved to Napier. Her husband had become extremely ill with Guillean Barré Syndrome in

Invercargill, and he found Invercargill winters were too cold. In Napier, Verona 's husband established a rare book shop. The two ran the shop for 17 months, although she had doubts that her secretarial-based skills would be suited to the work of running a shop. However, when she began to work in the shop, she quickly picked up additional techniques.

Further, her secretarial skills had little time to gather dust. During the first week she became involved with the practical needs of her next door neighbour, who had arthritis, and the local branch of the Arthritis Society, on making her acquaintance, quickly found themselves a secretary.

Towards the end of 1983, DPA began to operate in Napier and Verona withdrew from the Arthritis Society, switching instead to being secretary for the branch. It is a position she still holds, in addition to being a current member of the national executive committee for DPA. This, in addition to her voluntary involvement with another seven organisations, means a huge amount of unpaid work. Verona estimates 50-60 hours a week are spent in her office, at meetings, or at speaking engagements to service clubs or schools.

That the substantial amount of unpaid work she contributes receives little recognition, even penalty from government agencies incenses Verona:

> I think I've always been a volunteer and I've never looked for payment. Last year, when Social Welfare cut my benefit by $700, and then asked me to get help from my community group, I saw red, because as a volunteer you don't expect payment. But if they paid me for the hours I worked, and said it was work. (46)

She further points out that she contributes, including through taxation , and she is "not really doing anything for myself. I'm really doing everything for everybody else"(46).

Verona is aware that as she and her husband both age, pain and more limited mobility are very significant.: "he's getting very stiff-ageing quickly I should say". She prefers to focus on the more positive aspects of her situation "as long as I've work to do I can keep young" and is aware that "if I stop working I think I'll go downhill quickly, because I can shut off pain while I'm busy" (all 50). Because she sees her nature as happy, "I don't let things get me down too much" (51). She has spent most of her life doing things for others, and it has become an expectation that she will continue to do so.

The focus on keeping herself active has a further aspect. Verona has no confidence that she will get the state funded support services she might need: "I've never had any help from support services" (51). When she has made requests for equipment, the requests "were turned down every time" (51). Her husband has built the chairs, ramps, lifts and car adaptations she has required. A belief that "there won't be any support available" (51) is unpalatable, and it reinforces her desire not to focus on negative possibilities associated with age. She believes "we'll just have to face it [lessened capabilities] as we come to it" (52).

It is evident that Verona has disabilities but, to her, that has never meant there are any constrictions on living a whole life in a way that is consistent with her nature. She has a lifelong record of service and nurture in a wide variety of support organisations. She has married and had children of her own, and fostered many others. She continues to work for the rights of disabled people. While she regards herself as a very feminine person, she "will fight for the rights of women at any turn I can get" though "I'm not political" (both 54). She has lived her whole life the way she has wanted, and seen no contradictions in the way the different identities fitted together.

PART THREE

SUMMARY AND DISCUSSION

In the first part of this thesis, I have laid out a conceptual basis to my enquiry on what have been the experiences of older women with disabilities in relation to work. In it, I have traced the historical development of thoughts, attitudes and practices in relation to disability. I have also discussed current issues in relation to disability, gender, age and work. The context-setting of the first chapter raises issues of identity and power. I discuss the formation of identity for disabled women in both conventional and alternative ways, suggesting an alternative approach that incorporates diversity within an individual's identity. The chapter on methodology shows how I have shaped the enquiry in a manner consistent with this conceptual critique, through the method of audiotaped oral histories.

The second part provides condensed versions of the narratives each of the women told. The narratives are drawn largely from their audiotaped interviews. Not only do they provide a summary of the life stories, but also they are written to reflect a 'sense' of each woman and how she presented her story.

In this third part I discuss in more detail what can be drawn from the interviews, and how the interviews respond to my initial inquiry. This discussion is in terms of what is said in the interviews, what issues are raised by what is said, the settings of the events discussed, and the settings in which the stories have been told.

Part three has two sections. In the first section, I have sited the experience of disability in post-colonial Aotearoa/New Zealand. This part gives an overview to the way attitudes towards disability have impacted on social currents and policy. It thus constitutes a link between the narratives in Part Two and the discussion of themes and concerns in Part Three.

In the second section, I analyse and discuss the narratives and what they have to tell: the experiences of older women with disabilities, and the issues they highlight.

I have identified and grouped a number of themes arising from the narratives. Similarities, differences and comparisons and questions are addressed. The range of the stories is very large indeed. The themes which I have identified as arising from the disabled women's narratives are consistent with the literature reviewed in the first section. Given my knowledge of the community of disabled women, the themes were not unexpected. However, the precise configuration of themes and their interrelationships is drawn from the narratives, rather than expectations.

What the stories raise for any one woman's identity is worthy of detailed attention but that is not the purpose here. Rather I look for some of the common themes among the women and draw them together. I have not attempted to derive conclusions: given my methodology such an act would hardly be justified. The interviews are the ultimate 'product' and they exist as very effective testimony to the women who tell their stories.

1. DISABILITY IN AOTEAROA/NEW ZEALAND: THE IMMEDIATE SETTING

Beginnings

In the first chapter, the history of connections between negative thoughts about disability and negative actions was drawn together from the literature. In this section I return to the sequence, and relate it specifically to disability in Aotearoa/New Zealand. The siting of this section is deliberate: this section serves as a link point. In highlighting thoughts, attitudes and events, in this country, within the last 150 years, a context is provided for the narratives which have been laid out in the previous section. It further serves to give background to the analysis and discussion of the following section.

For centuries, workhouses, houses of correction, and large hospitals contained many disabled people in Europe. In the early days of post colonial Aotearoa/New Zealand, there were not suitable conditions in which to replicate this situation. There was a much smaller population spread throughout many rural and isolated settings, and there were not the substantial numbers of settled wealthy people to practise philanthropy and endow institutions.

This meant a degree of tension as the colony began to establish its patterns of social service provision. Duncan McGregor, Inspector-General of hospitals, and a senior health bureaucrat at the end of the century commented on this tension in 1898:

> While the traditional spirit of *laissez faire* was still powerful, it was gradually found that the social sanction (*richesse oblige*) was too weak to enable commercial charity to make up for the effects of justice....Some of its [social justice] most potent elements at home were incapable of transplantation here. (cited in Tennant, 1997: 14)

While attitudes to disability may have been successfully imported from Europe, the ways of operationalising the attitudes into policy required adaptation to new circumstances.

Disability had not been welcome in the new colony. European migrants were expected to be hearty vigorous, self-reliant, productive and independent. Disabled people were not seen to be any of these, constituted a drain on scarce financial resources, and were thus not welcome. A report from the Auckland Committee on Pauperism (1886) was clearly unhappy that numbers of disabled people were in Aotearoa/New Zealand. In blunt terms, it rejected "the old and the lame, the blind, the infirm and the sick have been thrown on our shores...many who ought never to have left home for a colony" (cited in Pirie, 1977: 478).

Regardless of whether or not they were welcome, sick, injured and disabled people were certainly present, And some response was necessary. In general terms of a concrete response to need, modification of European patterns of provision were required where there were neither large concentrations of population nor the availability of finance. The chief pattern was thus of voluntary, local or provincial response made to specific needs: for example when colonists were disabled in fighting, or in work accidents. Tennant (1997) traces this early provision, and notes that it often evolved into a situation where the state took a leading role.

Charitable Aid And Institutions

In terms of disability, the system of "charitable aid" that evolved constituted a major avenue for provision. By the 1870s "charitable aid", which had a considerable number of similarities with European Poor Law had begun to coalesce. In 1885, the concept was formalised in the Hospitals and Charitable Institutions Act. The Act set up a system of relief that came from a variety of sources. To local rates and voluntary donations were added contributions from central government. They were administered through local hospital and charitable aid boards (Tennant, 1989: 2). People were either helped in their own homes, or in

hospitals or benevolent institutions such as the Costley Home for the Aged Poor in Auckland.

Institutions such as the Costley Home had gradually appeared with an increasing population. The first of these were government-run lunatic asylums from the mid 1850s on. In these asylums, people with disabilities other than psychiatric conditions would be found. Some of these institutions were focussed on specific conditions, such as the Jubilee Institute for the Blind, or a specific concern, such as education[64].

Some institutions were run by voluntary organisations. Over time, government took on greater responsibility for provision, but voluntary organisations retained substantial involvement. They did not, however, undertake separate provision, and a relationship between the two parties, described by Tennant (1997) as long and intricate, evolved.

An example of the interrelationship is seen in the work of the Sisters of Compassion. When Suzanne Aubert and the Sisters of Compassion built their Home of Compassion for chronically and terminally ill adults and children in 1907, they obtained considerable financial support from donations. While government did not directly contribute, support, in the form of mortgage guarantees, came from Liberal government figures like Joseph Ward. (Munro, 1996: 263). Later 'establishment' support for the Home of Compassion came from judicial figures such as Charles Skerrit, (later Chief Justice), and Governor General Lord Plunket.

Institutional care of disabled people remained an significant expression of a societal response to disability in Aotearoa/New Zealand. Increasing provision

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[64] For example, institutions for the education of feeble-minded children at Otakaike (1907) and Richmond (1916).

through the state has continued in the provision of large psychiatric and psychopaedic institutions throughout most of this century.

Voluntary organisations continued to be a significant feature in a disability context throughout most of the 20th century. Many organisations such as CCS, IHC and the Royal New Zealand Foundation for the Blind have sought to advocate on behalf of their respective constituencies, often also providing disability services. Voluntary organisations have continued a record of complex interrelationships with government.

In the attitudes to disability accompanying voluntary provision, a certain sense of charity, middle-class rectitude and some rigidity are discernible. Tennant points to how such organisations "felt free to reject cases which they regarded as unattractive, undeserving, or simply 'too hard'" (1997: 17). From this perspective, 'voluntary' has not indicated any deviation from the orthodox attitudes to disability.

Eugenics

An influential factor in the history of disability in this country, in both attitudes and policy, was the rise of the eugenics movement. Just as the new colonists of Auckland did not want disabled people in the country, so eugenicists would prefer for them to disappear. Darwin (nephew of Charles) (1925) summarises this stance:

> There are many kinds of people that we do not want. These include the criminal, the insane, the imbecile, the feeble in mind, the diseased at birth, the deformed, the deaf, the blind. (1925: 25)

In the first part of the 20th century, eugenic theory gathered widespread popular currency in Aotearoa/New Zealand. It was consistent with the orthodoxy of the times, but acceptable across a wide range of opinion, from radical to conservative. When the Eugenics Society was formed in 1910 in Aotearoa/New Zealand, it

gained support from such diverse individuals as Truby King, Rev. Cannon Curzon-Siggers, Sir Robert Stout[65] and Dr Emily Siedeberg[66] (Temple, 1981).

Eugenic thought, which was negative towards disabled people, and others it considered 'unfit' to breed was translated into Parliamentary debate and, eventually, to restrictive legislation. In 1911, the Mental Defectives Act indicated political recognition of eugenics concern. It defined seven categories of 'mental defectives', set out measures for their control, and provided for the extension of the law to a wide range of disabled people[67].

In 1924, a Committee of Inquiry into Mental Defectives and Sexual Offenders recommended sweeping powers in the lives of many people with disabilities. Eugenics boards would have the power to order ongoing custody for people adjudged feeble minded in a farm or industrial disability colony, or order sterilisation for a range of people, mostly disabled in some way, who "ought not to be allowed to reproduce" (AJHR, VIII H-31A, 1925: 24). Legislation was not enacted, for ultimately imponderable reasons[68].

After World War Two, there was a rejection of a legislative enforcement of eugenics principles. Many people realised the huge scale killing of 'unfit' people in Nazi Germany, which had been facilitated by its 'model' eugenics legislation, and were unhappy with the connection. There was a move away from eugenics enactments or association with a school of thought where there had been unwelcome consequences.

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[65] Robert Stout was a liberal politician, and one of the country's attonerys general

[66] Emily Siedeberg was the first woman to graduate in medicine in this country. She was active in the Society for the Protection of Women and Children, and saw eugenics from a feminist perspective (Temple, 1981: 17)

[67] The six categories covered persons of unsound mind, persons mentally infirm, persons socially defective idiots, imbeciles, feeble minded and epileptics. The further provisions would extend the act to include the deaf, dumb, blind and moral imbeciles

[68] Parliamentary debates of the period suggest that impending economic woes were a considerable factor

There was not, however, complete repudiation of the theory of eugenics: Temple (1981) observes that "the eugenic creed and all that it implied inevitably touched the lives of many New Zealanders (1981: 84). The people whose lives were heavily touched by it were disabled people, with this being evident in a general proscription against disabled people being seen as sexual beings, or having children and raising children.

Rehabilitation

A further influence seen through most of the century was a drive towards rehabilitation. This is now a term with many different definitions, and dimensions (see Moore, 1995). But a review of rehabilitation over much of this century (Pirie, 1977) has linked it predominantly to work. Such a focus has been particularly apparent in relation to soldiers

After World War One, soldiers returned in large numbers, and needed to re-establish themselves. There was strong and sustained popular support for the returning heroes and, a department of Soldiers 'Re Establishment was set up to treat and re-train returned servicemen for employment. However, government funding trailed public support and sustained pressure from the Returned Servicemen's Association (RSA) was necessary to establish the Soldiers Civil Re-establishment League in 1930 (Leadley, 1948).

At this point, gender differences in response to rehabilitation became apparent. First World War nurses had also sustained war injuries, but there was little thought given to their return to paid work. Although there were stereotypes of women which placed both them and their domestic labours outside any relationship to employment, the picture was illusory. Many women, particularly working class women, had a range of reasons to undertake paid work (Eldred-Grigg, 1990). In ignoring these realities, rehabilitation in effect set gender differences in place.

While the rehabilitation of women on war service was more apparent after World War Two (Leadley, 1948) it has remained a comparatively minor theme.

The Soldier's Re-establishment League became the Rehabilitation League after its scope was enlarged in 1954. From that point it also offered vocational rehabilitation to civilians. Such a change may be indication of a need for a consistent, coordinated approach to rehabilitation, but this proved an elusive goal. The Rehabilitation League's approach was later encapsulated by Hunt (1988) as "suffering from a lack of overall planning and policy" (1988: 794).

Rehabilitation is of particular relevance to disabled women because in it, a series of images about disability and work has become, to some extent, intertwined with images of women and work. The resultant mixture has not been encouraging, and the contradictions of woman-as-nurturer (Fine and Asch 1988) and disability-as-dependent (Morris, 1991) have remained. The focus on rehabilitation for employment has similarly remained, and a medical focus has similarly predominated (Moore, 1995). Social and community rehabilitation being been minor components.

When the Accident Compensation Act was passed in 1972, it had been an attempt to address the problems arising from the law relating to workers' compensation and particularly summarised in the 1967 (Woodhouse) Royal Commission of Inquiry. The Act has since become enmeshed in the ongoing debates regarding rehabilitation policy, which is further set within of recent changes to disability support services policies (see Shipley and Upton, 1992), and debates about funding.

Medicine

The influence of medicine has been a recurring theme from the earliest times, from the local and voluntary provision, through the setting up of voluntary organisations

such as CCS (Smith, 1979), and within institutional care (for example, Riseborough, 1986). Medical practitioners were prominent among the supporters of eugenics policies (Temple 1981).

A further aspect of medical influence on disability has been in relation to the cost of medical care. When the 1938 Social Security Act provided (almost) free doctors visits and hospital care, the needs of disabled people who required such services were better addressed. This came with some 'strings, however, in terms of accepting medical authoritativeness about disability. Doctors or other medical people have, for many years provided certificates of 'authenticity' of disability to government departments who required them in order to approve benefits or other entitlements. Their status as 'approving agents' has been written into legislation, such as the Accident Compensation Act (1972) and regulation or policy manuals for government departments such as Social Welfare.

In this section, I have again shown a link that begins with negative thoughts and attitudes about disability, and commonly translates into legislation, policies and practices that are disadvantageous to women with disabilities. The section has shown this link in the setting of Aotearoa/New Zealand.

2. READING THE STORIES: ANALYSIS AND DISCUSSION

In discussing all the stories, and what they display in terms of shared themes, I have looked particularly at what they reflect about power and identity. The stories differ greatly, and each story was told in a different style. The purpose of the interviews was to inquire into the actual experiences and thoughts, along with the reflections generated during an interview. Topic areas, but not specific, predetermined questions were canvassed. Therefore, analysis is not based on predetermined categories. Rather the stories or texts have been interrogated.

What emerges from this process, are a number of common and interconnected themes.

The discussion and analysis of the themes emerging from the narratives are grouped into three clusters. The first cluster looks at invisibility and at, attitudes towards disability, in terms of how those outside conceived it, and how the disabled individuals themselves felt about it. From this, I go on to look at expectations and effects of these attitudes. I have chosen to draw out these aspects in distinct sections in order to assist the analysis. But I acknowledge that the distinctions are arbitrary, and that actual processes are interrelated to a far greater extent than the headings would suggest. I therefore note these interconnections, focussing in particular on work, as it was initially identified as a central occupation in the lives of most adults, and questioning therefore gave emphasis to work.

The second cluster examines the way disability, gender, age, work were seen to relate to one another. These aspects, in total, comprise my research question: enquiry about the experiences of older disabled women, particularly in relation to work. The linkages or non-linkages can be set alongside the material in the review of literature: there is overall consistency between the two sections.

The third cluster is about living a whole life, and about a sense of identity. In contrast to the first two, it looks the way seemingly-disparate parts of identity fit into a whole.

Invisibility: Missing A Disabled Presence
If issues are not discussed within society, they remain perpetually invisible. As a child growing up in Christchurch, Maori issues remained so invisible that it is difficult even to remember if any Maori children were my schoolmates. The history of what happened to indigenous people at the hands of colonists in the South

Island, as detailed by Evison (1993) was unknown to me or to my classmates. In a similar fashion disability has remained persistently at the edges of everyday living, invisible to both disabled and non-disabled alike. The invisibility of disability has been a part of these women's lives. While disabled people have always been present, they are often not seen to be present.

As children, whether or not they were disabled at that point, most of the interviewees have few memories of disabled adults or children. Dianna has almost no memories of disabled people in her childhood, and only one dim, half-remembered image of a male amputee in some public position from early in her adult life. Although both she and Verona had mothers with terminal illnesses, both mothers were "ill" rather than disabled.

Verona talks of how disabled children were, in her childhood, not usually seen: "usually in the back bedroom" (16). Her memory of how the invisibility was effected is similar to Sophia's experiences of disabled children in the Outer Hebrides. On the Islands, the disabled children and adults were enclosed within the family. They were not often part of the everyday community life as other children were. There was a certain ill-defined sense of protectiveness to the way in which families enfolded their disabled family member. Sophia did not get to meet these disabled people until their family trusted her.

As a teenager at a Correspondence School regional gathering, Karen remarked this protectiveness, and how it could be unhelpful. She saw a young man with cerebral palsy, "probably perfectly intelligent" whose mother "hung on his every move...I can see how smothered he was by his mother. I could see the resentment in his own face". She saw another young man, also with cerebral palsy who had completed his Master of Arts degree, and thought the first, "over-protected" young man would not achieve as much as the young disabled man who had been less restricted.

For Sophia and Olive, both born in Britain, disability was much more visible. Following two world wars so close to home, there were many more disabled servicemen. Certain kinds of physical disabilities, notably amputations, were visible. Sophia remembers women were also at risk of war-incurred disability. Women who were responsible for barrage balloons, and her mother was one of a number of air-raid wardens whose jobs also meant exposure to combat fire. But such women who were disabled by war were not visible or remembered figures: the disabled people Olive and Sophia saw were males.

Even that degree of visibility of disabled men was confined to a few settings. While they were have been more evident on the street or in other public venues, they were rarely seen among 'working people'. The people who served in shops, were behind desks, managed banks or taught in classrooms were non disabled.

This absence from workplaces might, at times, be the result of policy decisions. Karen encountered this in teacher training, which she could not undertake while educational policy required a physical clearance for teacher trainees. Such a clearance had not previously been available to a woman with polio, cerebral palsy, or other physical disabilities. Only when that policy was changed could Karen begin to train.

Grace remembers a number of disabled people with whom she mixed. She knew a young woman neighbour with physical disabilities in her home community. As a young adult, she chose to share activities with disabled people. She went to organised social and sports club events specifically for blind people, and regularly assisted in other activities they requested, such as clothes shopping. She worked in a factory with an intellectually disabled man. When she was wearing an eyepatch, she noticed a few other visually impaired or blind people with eyepatches. Her membership of organisations for blind and disabled people also

involved extensive contact, while her involvement with the Assembly of People with Disabilities (DPA) meant she was in contact with many people with all sorts of other disabilities.

Discussion

There is some similarity among the women in their knowledge of disabled people, alongside a number of contradictory features. An overall impression is that disability was not a commonly-noticed feature of the societies in which the women have lived. There is a certain difference between the small numbers of disabled people who were remembered and the higher numbers of disabled people who actually existed.

It is a further feature that how much the disabled women did or did not notice other disabled people bore little relation to the presence, or absence of disability in themselves. Ann, with a lifelong and visible disability mentions few other disabled people, while Karen, disabled in childhood saw a number. Dianna and Olive, both disabled later in life show a similar divergence in experience: Dianna remembers seeing few disabled people, Olive saw greater numbers. But in both pairings, the number of disabled people noticed was small in relation to the disable people who existed.

There is a paradox highlighted by the data. It is not that disability is so scarce that it is invisible, but that, although disabled people are present, they are invisible. Such invisibility is, I argue, consistent with Le Compte's (1993) observation that marginalised or invisible people have "voices...silenced because of social stigma or inferior status" (1993: 10).

Attitudes

For the women to know of so few disabled people in the community raises the question of what was understood of disability, that it remained so far from the eyes

of day to day living. When disability <u>was</u> discussed, the perceptions were almost all negative. The women experienced this negativity as a constant orientation from the thirties until today. The attitudes they heard conveyed are largely negative, but they are present over a very wide range. At times, there was a contrast between negative 'external' messages conveyed by society and more positive personal attitudes to disability.

There are two aspects to the messages: what the actual message was and the way in which it was delivered. An example of this is in the very hostile attitude Sophia's mother displayed regarding certain forms of disability: "one didn't talk about epilepsy in our family. My mother seemed to have an idea that epilepsy was one of those things that was 'the sins of the fathers visited upon the sons' ". Since Sophia recalls a sternly disposed mother in other attitudes: she found female children disappointing, it is probably little surprise that she would not approve of other deviations from 'ideal'.

Anne's mother also had strong views about disability, and little hesitation in articulating them frankly and forcefully. She could tolerate certain disabled people, but did not like those who were, in her opinion "pushy disabled people" . Precisely what constituted a pushy disabled person was less clear, but the clear implication was that disabled people should remain silent and deferential to whatever impediments were present.

At Karen's primary school, attitudes took the form of fear and prejudice. The reactions of schoolmates had much of the characteristic schoolchild's aversion anything different. But in addition, the reactions mirrored the attitudes of the adults. There was a fear, part ignorance, part superstition in their refusal to touch her hand lest the "hoppers" that they believed had carried her polio had lingered around her person waiting to infect someone else. Children from the school also

bullied and hit her because she was unable to move as they did, taunting her weakness and inability to respond physically.

In contrast, Grace encountered more inclusive attitudes to disability. A neighbour's daughter with obvious mobility disabilities regularly visited neighbourhood houses, and did not appear to be marginalised by the semi-rural community. Grace's partial sight was not stigmatised. But when, as an adult, Grace progressed from partial vision to blindness, she encountered very different attitudes. Her husband thought that to be disabled was to be quite helpless, and to undergo continuous suffering. Death would be preferable to disability: "He felt that what had happened should have been the end of my life, and I should have been...throwing myself in the sea". In her subsequent paid work, she constantly encountered people who believed disability was equivalent to inability. Thus her workmates did not believe she could possibly assemble packaging, or handle a sharp knife.

She further saw how some disabilities, notably intellectual disability attracted even more heavily punitive attitudes from non-disabled people. An intellectually disabled co-worker was heavily bullied with a flurry of conflicting demands, and was treated with contemptuous language by others on the staff.

As a child with a squint, and wearing patched-eye spectacles prescribed to correct a squint, Olive was isolated and bullied by her schoolmates. As Karen had also found, her differences were regarded as a sign of inferiority. To this encounter with invidious attitudes, she could add the mistrust used to talk about disabled people. When she encountered some disabled servicemen busking for money in public, she was told she shouldn't give them money, because they were probably making 'plenty' of money out of begging; more than they deserved. In these comments there is severe judgement on what these people deserved.

When she became disabled in her forties, Olive encountered a further set of attitudes to disability, strongly flavoured by medical considerations. She found that disability was a power-and-control issue: "the loss of my ability took away my equality", and medical professionals were sure they knew all about disabled people. Because these professionals had some knowledge of anatomical states or physiological requirements associated with a given condition, they felt that gave them unlimited authority over all aspects of disability and disabled people.

Sophia also discovered the negativity of medical attitudes to disability in mid-life. She found herself treated as though she was owned: unable to run her life and make her own decisions. She too found the sudden loss of autonomy extremely galling, and held up the possibility of legal action so that she could regain some measure of control of her own body.

Even when women considered themselves in charge of their health care, as Ann has done since her twenties, medical 'in charge' attitudes can undercut a woman's management of her own body. Disability can be seen as a site for medical management. For example, Ann's doctor omitted to explain why a constant medical complication that concerned her arose as a consequence of her particular impairment, and what she could do for it.

Grace discovered, through her employment alongside a man with intellectual disabilities, that some forms of disability attract a more punitive attitude. This is echoed in attitudes to invisible, neurological or psychiatric disabilities. For example, Olive's father was "shellshocked" in World War One, and was more than ten years in a convalescent home for soldiers after his return.

Common attitudes in the British Army of the period, and understanding of the ongoing effects of psychiatric disability were minimally developed, and it seems likely he will have encountered little effective treatment. Barker (1991) writes that

the 'treatments' of the period were repeated electrical shocks, strict discipline or corporal punishment. There was an underlying attitude that such disorders were somewhat wilfully held, and could thus be cured by the exercise of sufficient willpower. The attitude was widely held in both military and civilian life. So when Olive remembers her father's unpredictable rages, her belief that he could have controlled these rages through greater self discipline is consistent with such a perspective.

The shock of battle or imprisonment, now commonly called post traumatic stress disorder, was also in evidence for Sophia. She recalls soldiers of World War Two who had perpetual nightmares, depression and uncertain temper from their experiences. There was still a sense of willpower-control for such conditions, but official attitudes were less punitive towards psychiatric disturbance than during World War One. Attitudes of family and friends towards disability in the mind were still of shame, fear and bafflement.

The attitudes resonated with Sophia's own circumstances. From childhood she had an invisible disability, and her attitude towards it was a mirror of common attitudes in society towards disability. Her psoriasis was something shameful, so she hid its existence from most people. She minded dreadfully that she had it, and it constituted a huge barrier to self esteem, and to intimacy. The reaction parallels her mother's fear filled repudiation of epilepsy.

Discussion

The attitudes to disability seen by the women, in both society and in family circumstances were overwhelmingly negative. It is hardly surprising that such attitudes were taken on board, to varying degrees. The words Australian singer-songwriter Judy Small uses to describe the impact of attitudes to women encapsulates the process of internalisation:

And you never thought to question it

You just went on with your lives

For all they taught you who to be was mothers, daughters, wives

And you believed them.

Likewise women with disabilities believed, to a considerable extent the negative images of disability.

The intersection of attitudes to disability with reproduction and sexuality is illustrates this point. For over thirty years, eugenic arguments were particularly influential on public thought. They were heavily opposed to disabled sexual or reproductive activity. It is then of little surprise that negative attitudes were encountered by the women.

Attitudes And Expectations: Sexuality And Reproduction

Anne, with visible and from-birth disabilities, encountered contradictory and "revolting" attitudes to sexuality and relationships for disabled women. At the time, the conventional attitudes were that young women "shouldn't" engage in sexual practices. Indeed, to own to sexual feelings was regarded as somewhat distasteful. The prohibition was applicable to all young women, so "shouldn't" applied to young disabled women too. But Anne found that some young men felt that sexual activity could and should be engaged in by a disabled woman. They told her that such activity would be good for a disabled woman . They implied they would be willing to undertake this 'therapy". However, the benefits of this activity were not seen to extend into marriage or a serious committed relationship. Marriage, and all that the term implied in terms of commitment was not considered a factor relevant to disabled women.

The attitudes Verona found in relation to marriage and children also show a reluctance to consider disability in relation to reproduction. Her future mother-in-law assumed that disabled women couldn't have children, and would not, therefore, marry. Since she wished her son to have children, he could not marry

Verona. Such attitudes carry echoes of eugenics concerns about disabled people and reproduction. The concerns also relate to predominant social conceptions of 'femininity'. To be a 'proper' woman of the 1950s, having children was an important part of a female role. A disabled woman was not, in this definition, a proper woman.

Karen, like Ann, heard that sexual activity was a heavily sanctioned area, where respectable young women did not engage. But Karen not only took part in sexual activity, with the consequences of pregnancy outside marriage, but then did not behave 'properly', so that she encountered a further set of negative attitudes. In the attitudes she experienced were both attitudes to women and sexual activity, and attitudes to disability and sexual activity.

When Karen chose to keep her child, attitudes were even more negative. Sole parenthood, such as she chose was not socially acceptable unless the mother was widowed, so she attracted additional and ongoing sanction: an attitude applying to any woman who displayed such behaviour. But beside this, there was a distinct strand of concern about being pregnant and disabled. Her family was worried that pregnancy in a disabled woman would be too great a strain. They were also concerned with the ongoing bodily and mental demands parenthood would make on her.

Attitudes and Expectations: Gender, Age, Class

Attitudes and expectations towards disability showed the influence of other factors, such as gender, age, or class. For example Grace, from a working-class family, recalls family attitudes of 'tolerance' for disability. Additionally, her mother valued academic success highly. But while scholastic attainment was expected of her brothers, there were not those aspirations for her "I know great things weren't expected of her because, you know, she's got eye problems".

While Grace's disability was a factor, somewhat stereotyped class expectations seem also to have been of influence. All family members were oriented to working in a practical, manual way. Grace expressed a preference for variety and activity. She was young, and towards the end of the 1950s, with an expanding economy, factory work provided these aspects and was a ready option for a young working class women with basic secondary education.

In contrast, when she became blind, attitudes and expectations coalesced in a different pattern: disability and, to a more circumscribed extent, sexism were key influences. Co-workers and managers were convinced her disability meant she would not be able to retrain to work, particularly if it had any degree of complexity. Similarly, they were sure she could not increase the range of her skills, nor could she operate independently and safely without assistance.

Discussion

The experiences of Ann, Verona and Karen are consistent with Sawicki's (1982) analysis of woman's sexuality and difference. Sawicki (1992) has pointed to the way power and control was largely related to the way female sexuality was displayed, rather than whether female sexuality, in itself, existed. However, it is open to question and more detailed analysis whether the control of disabled sexuality has been set at a similar 'level'. The work of others, such as Morris (1991, 1996), Fine and Asch (1988), and the ongoing body of eugenics thought suggest otherwise: that control may be related both to display, and existence of disabled sexuality.

Attitudes, Expectations And Effects As Seen in Work
Paid Work

Dianna was aware that general attitudes to disability saw it in terms of shame and pity. That did not match with the very positive personal attitudes she developed from her experience of her mother. Later, when she found she had disabilities, she

would characteristically ignore negative attitudes she encountered at work. She might occasionally choose to address the expectations by emphasising how she was well able to perform her role, and her impairments were no hindrance to this position: "I wasn't a pianist or a waitress or a seamstress or anything". Her status in an independent position at the workplace, and impressive qualifications for the position, in conjunction with her own tendency to ignore possible discrimination may well indicate how advantages of class can minimise potential disability discrimination.

Expectations were clearly seen in relation to work, both paid and unpaid. Karen's mother had passed to her daughters a belief that 'girls can do anything' and a career would not be confined only to nursing or teaching. But when Karen encountered a vocational guidance counsellor, she found very clear and circumscribed expectations of what was suitable work for a disabled woman. Karen felt such 'suitable' work constituted an "occupational ghetto" for disabled people.

These ghettos were often with particular employers. Karen noted one of these was the Railways Department where, coincidentally, Grace found employment, and also noticed how it employed other disabled people, mostly men. The absence of disabled women in public life-serving in shops, behind counters or office desks provided its own message though. For most of her employed life, Karen 'passed', because she was positive that to openly acknowledge disability would mean she would not be employed.

Grace's co-workers expected she would not be able to perform any but the most basic tasks, and that she could not learn new tasks. They further expected that she would require special, compensatory treatment. So when she was to be made redundant, they asked the advice of a disability service provider about how to 'handle' telling Grace. Anxious workers, drafted to provide additional support

offered Grace cups of tea in diuretic quantities, and Grace needed to tell the manager that she was to be made redundant, as he was unable to do so.

Dianna and Olive did not acquire disabilities until later in life, and Sophia's disability was in a less active state until later life. To these women, where disability was not a particular factor in the first part of life, expectations and effects in paid work began by being more influenced by gender differences. Both Dianna and Olive saw how women generally went into lower status jobs, and on lower pay than men. In the church, which paid neither sex generously, Dianna was paid at a lower rate than men. In the bank where Olive worked, men were in charge, and were paid much more. Olive also noticed a lack of a career path for women: they remained in low level jobs, and lacked equitable access to benefits such as pensions.

Sophia and Olive, both of whom came from Britain, had differing experiences of pay equity. Sophia, who came from a middle-class background experienced more opportunities for equal pay and non-traditional occupations in Britain than did Olive. Her mother had not shown sex-role stereotyped expectations of what Sophia 'should' do. Rather, the approach to any potential career was one of information seeking and problem solving. Sophia trained as a marine engineer in the 1940s; one of the first Scotswomen to do so, with positive parental attitudes. She earned at the same rate as male apprentices. By contrast, Olive's very poor working class background gave her few opportunities to escape to non-conventional occupations. Expectations were of the need to earn money: any other consideration was secondary. So that the Bank of England had a large gender pay gap was very much a secondary factor..

Anne went through her paid working life in a succession of professional positions where equal pay was never questioned. Expectations of her related to her disability, at times subtly intermingled with gender. While the expectations were

framed in less overtly discriminatory terms, their intent was evident. Co-workers felt her disability would colour her professional practice; she would "project her problems" on to her clients. She was thought to be unable to work in certain 'at risk' situations. And gender combined with disability in a manner that abused power relationships when the way she needed to deal with inaccessible but necessary surroundings were cast in terms of her obtaining sexual gratification by her clinical supervisor.

Verona's disability had considerable impact on her paid work. She had wished to become a children's nurse, but after her legs were amputated, and she was ready to undertake paid work, the disability service agency that had 'claimed' her decided what employment she would undertake. The employment was thought to be appropriate for a disabled woman, and she did as she was told. Obedience to the commands of others in such matters was not solely a matter of disability. Non-disabled young people might have their jobs chosen for them by parents.

In her adult years, when Verona had considerable skills and experience in a secretarial capacity, she agreed to an urgent entreaty to fill a secretarial position. After a while she found that although she was doing the same job, she was paid at a substantially lower hourly rate than the previous incumbent because she was disabled. Further, the organisation, which provided sheltered employment for disabled people, entered her as a client of the service on their statistical record. This is a somewhat more blatant example of an overall experience of the disabled women: attitudes, expectations and behaviours have provided varying negative consequences that regularly include discrimination in employment.

Discussion

Statistics NZ (1997a, 1998a) shows that disabled women in New Zealand have, on average, very low incomes, and limited employment in traditionally poorly paid occupations. The experiences or expectations of some of the women do not

always conform to this pattern. However, the 'snapshot' average provided by the statistical data could by no means capture the variations in individual circumstances with differing combinations such as education, class and family.

The complexities in attitudes and behaviours highlights how there are often interactions arising from different factors. Relevant literature such as Morris, (1996), Barton, (1996), and Lonsdale, (1990) tends to attribute the situation principally as coming from one factor or another[69]. Yet the women here describe lived realities that are less 'flat' and unidimensional than the literature implies; the experiences are more open to ongoing change. For example, earlier experiences where there are limited options related to class position, and gender inequities in paid work (wages and status), can change to a situation where disability factors, of particular impact in obtaining paid work are more important, gender has more limited significance, and age appears to be of positive influence. The relative significance of factors such as disability, age and sex operates on a far more complex front than might be expected.

Unpaid work

For disabled women, as with women overall, unpaid work is a substantive issue. The women here accord it high importance. Olive lays out a relationship between paid and unpaid work where "you do whatever you have to do to earn money in order to do the work that you really want to do ...work is what you're here for , and what gives any of us satisfaction in life" (47). It was to her unpaid youth work (through Woodcraft) that she had accorded the highest importance. Then, after her spinal cord injury, she continued to support unpaid work because she still thought it was the most important thing to do, rather than because it was all disabled people could do.

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[69] It is true that disabled feminists in England such as Morris (1991, 1996), look for a more realistic way to describe the situation, other than having one 'ism' as the 'cause'. However, in describing a variety of other factors such as feminism or racism through a principal 'strainer' of disability, the effect is, I have argued, similar to using feminism as a principal explanatory factor.

As a sole parent, in the days before there was any state support for her, Karen had to continue in paid employment. While she does not assign a higher value to paid work, she has been largely in paid work. This has been a practical requirement. As a sole parent in the days before domestic purposes benefits were available, she needed to support herself and her son. Undertaking unpaid childcare at home was not a realistic option. She now is involved with disability, community health and social justice organisations, regularly her journalistic and publicity skills. Unpaid work has been the arena where issues other than being female, notably disability, and other social justice concerns could assume more importance.

To Sophia and Olive, when they were no longer able to take part in paid work, disability became a more influential factor. Unpaid work was, to some extent available, but it was of somewhat limited nature. Both Sophia and Olive chose their own paths in this. Olive put her efforts in an educational arena, involving young people whenever possible. This related substantially to her previous youth work in the Woodcraft Movement. She also conducted disability awareness for younger people. The disability advocacy that Sophia took up was a forthright support for new services, and for the place of disabled people in deciding them. To Sophia, it represented a new direction: she had undertaken unpaid work in the form of childcare before, but little beyond this. The unpaid work both women undertook is in the arenas where a majority of disabled women contribute (Statistics NZ, 1998a).

Verona has been in a position to be a full time parent to her three sons. Concurrently, she has undertaken a huge amount of additional unpaid community labour. In addition to caring for large numbers of neighbourhood children, she has cared for refugee families, fostered for social welfare and church agencies, and

provided short term care for disabled adults and children. She has been involved with many other organisations in a secretarial and organisational capacity.

Anne has not sought involvement in unpaid work but has nevertheless done large amounts of unpaid "committee work", and held other offices for voluntary organisations. Dianna has undertaken similar organisational responsibilities. For both, the work has been in capacities that have some correspondence with their previous paid work. For both women, paid work has meant familiarity with participation on committees, running meetings, heading special projects, controlling boards, and organisational planning. In a similar way, Verona's secretarial and organisational expertise have been eagerly sought by numerous groups.

Although the work is seen to be of high importance by the women, they are aware of the constraints on it because of insufficient resources. Verona and Sophia, both being paid government benefits, find it difficult to persuade government agencies to provide adequately for their transportation needs in relation to their unpaid work. Dianna and Karen likewise need reimbursement for expenses associated with these organisations. Olive went directly to the responsible government minister, so that she could continue provide unpaid remedial reading. But she became frustrated with having to repeat the "performance" annually, and eventually found a private charity to pay for her mobility taxis. Anne, who finds demands for her presence are nationwide, and who retains a considerable concern that she maintains her financial independence, will not undertake representation unless her travel costs are met.

Discussion

The issue of unpaid work and resourcing its costs, highlights power relations operating in two contradictory ways. First, organisational policy, has the definitional power; it can set its definition of a disabled person in order to issue

benefits. Second, however, it also has the power to take notice, or ignore the implications of its definition. For example, disabled women may be defined as disabled so that they are eligible for an Invalid's Benefit, (and unable to engage in paid work). However they are still able to undertake unpaid work. I have detailed in Chapter Two how disabled women participate in unpaid work at similar rates to non-disabled women, but are often required to face high costs of accessible transport. In effect, the additional costs of participation constrain the extent to which many disabled women can participate in unpaid work.

Much of the power in the women's lives has rested with others, who, have formed a conventional definition of disabled people. The way disabled people are expected to behave, what it is expected they are capable of and how they 'should' feel are imposed by others. What has also been a consequence of this 'other power' is an effective silence or non-presence of disabled people. In paid work, the women knew few other disabled people, and those who were known were rarely within the mainstream of the community, enjoying ordinary jobs, ordinary lives. In unpaid work, they did not comment on the involvement of other disabled women. Such absences lead one to wonder whether the group does exist, or whether that they are not really an issue. As Karen comments, in relation to the absence of disabled people from public life "you get your message".

While there was a certain degree of taking the orthodox expectations and their consequences on board, as Karen did when she 'passed' in order to obtain employment, the women often expressed anger, incredulity, or disagreement with orthodoxy. Sometimes they simply dispensed with or challenged conventional wisdom. Olive did this in disability awareness sessions, describing disability as a problem, or in publicly rejecting medicalised presentations at a conference of urologists. Such disagreement with assigned definitions may also indicate some alternative sense of identity. In the consultation phase which preceded the interviews, the concept of an alternative identity developed by disabled women

about themselves was regularly discussed and supported, but it remained largely a theoretical possibility. It is not unexpected, therefore, that an alternative sense of identity was not a strongly developed theme.

Disability, Gender, Age, And Work: Connections, Gaps

Connections among the various states: disabled, gender, age and how any of these relate to work show considerable variation. Some linkages are evident to some women and not to others. In other instances, potential linkages are not considered to be very relevant. Most, however, feel that there is some linkage between disability and other factors.

Age

Olive can see positive aspects in ageing; she believes it gives a dimension of maturity, an ability to be very balanced that is recognised by the students she tutors. They constantly evaluate her very positively. But she has misgivings about ageing, because the hospital where she lives is to be closed. The alternatives for residence and support services, and the extent to which they will respond to her needs as she ages are unclear. So she worries that insufficient money will be available to maintain her care to a comparable level.

The apprehension Sophia and Olive have about age is echoed by others. Dianna associates it with loss of independence, while Anne contemplates ageing and increasing dependency with pessimism. Verona too is apprehensive. She has ever-increasing restrictions on her mobility, a partner with chronic health problems and a lack of financial independence. She views age in terms of lack of choices.

In general, the women see being old as linked with being poor, and consequently with lack of choices and independence: age is clearly framed in terms of difficult material circumstances. Other than Olive's identification of a good aspect of age,

the overall evaluation is not positive. That means that the women tended to avoid contemplation of possible outcomes of ageing.

When there is an appropriate 'space' for people to consider age in greater detail, the comments tend to be more positively focussed. Thompson, Itzin and Abendstern's (1991) study of how older people view ageing shows many aspects of ageing, with positive comments being common. But the study contains relatively few comments on the perceived linkages to disability. The older people in the study appear to distance themselves from disability: they are old but not disabled. They regard disabling states often associated with age, such as stroke, as a manifestation of the ageing process. They regard themselves as old, (which is acceptable), but not disabled (which is not). Sophia's comment on the desire of disabled or older people to remain distinct from each other is consistent with the content of this study.

Disability And Age

Sophia is very definite in what she sees about disability and age: they are two distinct states, both requiring respect, but not interchangeable. Having experienced being labelled, first disabled then old, and treated on the basis of these labels, she found being labelled 'old' meant something worse. What happens had a feeling of finality:

> the professionals wanted to take control over you, and organise your life for you....You must start thinking about what rest home you want to go into, and you'd better start making arrangements to do this and that...this is so final. It means the end of the line, and the next thing is the box, and six feet under.

She also talks of how old people often do not want to be labelled as disabled when they see themselves as, getting older and a bit stiff. Similar sentiments are expressed by disabled people, who see being old as a more helpless or unwanted state than disability: "we haven't changed as a person with a disability, living our

lives as best we can. We don't want to be classified as elderly...why should we have another label?" Olive's reaction is similar: "I've always thought ...age is one thing, disability's another. Put the two together, and thanks but no thanks".

Age And Gender

Fewer links are made between age and gender. Sophia feels being an older woman is a relatively positive state:

> Because women generally outlive men, so there are more women around, so we are a force to be reckoned with, not shoved around as a group or something. I think men tend to come in probably for more being pawned and pushed around and sat on because they are a minority group in the elderly sector.

But in her own situation, Sophia feels that since she remains at home and in bed, the issue of gender is an irrelevancy. Since there is little interaction with others other than at home, and that is of very limited extent, social or competitive situations that would give meaning to gender are missing.

It greatly concerns Sophia that the being on a benefit brings what she experiences as considerable limitations. She finds the benefit inadequate, and with severe or arbitrary restrictions. Because of this, she feels choices and autonomy are limited. She further points out that if one is on a benefit before becoming a superannuitant, there will have been almost no chance to save or to acquire assets. These difficulties from the benefit system are also raised by Verona.

Karen finds the mixture made by age and gender is more complex; the two are overlaid by disability. Her symptoms of post-polio syndrome (PPS) became evident in her fifties, and when it was realised how they originated, she was relieved that she was not a 'neurotic' female, and that it was legitimate to look after her own body. She was a woman, but being older did not mean she felt free from such

common female stereotypes as the 'neurotic' woman; or that a woman should care for others but not for herself. In this instance, disability appears to have been the 'legitimating' factor in enabling her to take notice of and care for her own body's needs. To minimise the effects of PPS on her ageing body, Karen now undertakes a particular programme of exercises.

Anne sees the age-gender connection in terms that, like Karen's relate to a third, related factor: financial autonomy. She has, for many years, saved carefully so that she can have financial autonomy when she became old. She recognised that to be an older woman meant one was more likely to be poor, and to lack choices or autonomy. She comments, "what on earth my mother would have done if left on a simple old age pension I cannot imagine. She would have had the most miserable life". In addition, Anne's awareness of the extra importance of assets to older disabled women was combined with her ability to save. It has allowed her to sidestep a common female-age linkage of poverty. She is able to pay for the support she needs, and to the extent she desires

The importance of choice is also expressed by Dianna, though less explicitly. A legacy enabled her to do such things as buy a house, so she has been able to retain autonomy and a lifestyle in which she can continue to enjoy music, painting and cultural pursuits. She feels this is an unexpected benefit. Like Anne, she has always been prudent, but has not been in reasonably well-paid job where she could save much. She shows she is aware that age and gender are often related to an absence of money.

Discussion

The connection between age, being a woman and material circumstances is not just raised by the women: it is seen in other research material. For example, Jack (1982), writing on disabled women (up to 65) reports that 54% of the women she surveyed had an income less than half of the average female wage. This is

echoed in other material. In 1996, 71% of disabled women over 65 had an annual income under $15, 001 (Statistics NZ 1998a).

For Olive, a female parental role has remained a constant feature over time. It is significant in how she views age and being female generally. She is now a grandparent, and finds that for her to be present is as useful to her grandchildren as it was to her children in their growing up. She further illustrates the sense of being useful and feeling connected to others in talking about a woman acquaintance who saw community work to give her a way to be useful as she aged.

Although Olive has seen age and disability as very distinct, mutually exclusive states, she considers age and gender to be much more integrated. Thus she says:

> I certainly don't go round thinking about it at all. Not in that way, that sort of analysed way....No I just go along doing what seems to be the next thing that makes sense to me.

Disability And Work

I have written about disability and work in relation to expectations in the previous pages, in the context of attitudes and expectations. But this is an appropriate point to acknowledge the strong connections the disabled women saw between the two. Ann was very sure of what work, by which she meant paid work meant to her:

> It meant respectability for a start. It meant independence. It meant being stimulated, and not stuck someplace, powerless. That's what it meant. And that's what I would wish for all disabled people.

Grace's description of the nature of unpaid work is consistent with Anne's description of meaning in work. She says that unpaid work is neither clearcut, nor circumscribed. For unpaid work to be performed adequately, some resourcing is necessary. For Grace, this means she can get the equipment needed to

communicate in the job, such as optical scanners. She further feels unpaid work has equal status with paid work. It is of value because it undertakes the kinds of activities, for example advocacy, that promote independence, both for the recipient and for the worker.

Unpaid work is given considerable recognition in most narratives. Like most of the others, Verona is very aware that her unpaid work has positive value, both for those with whom she works, and for her disability community. Verona's involvement in unpaid work has been extensive and ongoing. A good feature of unpaid work, she points out, is that it is largely self-directed. Since she was not allowed to pursue her career choice, she found alternative ways to reach the same goal.

Olive, with a similarly extensive and self-directed involvement says unpaid work is "what you really want to do", while paid work is undertaken to earn the money necessary "to earn money to do the things you want to do". She holds a well developed, if less than conventional view, of how paid and unpaid work relate to each other.

Discussion

The status accorded to unpaid work seen from a disabled women's perspective is little different from the way feminists, such as Delphy (1984), Waring (1988) and Walby (1990) have approached the issue for women. They have sought to reframe a male-based discourse about work that more accurately reflects its meaning, and the value in society which it is accorded.

Disabled women undertake large amounts of unpaid work both inside and outside the home, as is seen in the 1996 New Zealand Household Survey on Disability (1997a, 114-5). There they found the most common form of unpaid work by disabled women within the home was housework. Outside the home,

administration and policy work were the most common forms of unpaid work[70]. It is not surprising that the disabled women interviewed undertake considerable amounts of unpaid work. Rather it is consistent with other data.

Identity: A Whole With Many Aspects

In recognising how identities of disabled, older and female all related to one another, Karen describes a process where she recognised the existence of one form of discrimination, which meant she was better able to recognise discrimination in other forms and then to make the connections with forms of discrimination that were not well recognised. Her earliest recognition was of sexual discrimination particularly in paid work, and then in its particular form of discrimination against unmarried mothers.

An awareness of racism developed as Karen made connections between work-based gender discrimination and racial discrimination: people avoiding her because of a Maori surname, and harassment of her 'Maori' (Pacific Islands) son as dirty or potentially criminal. As she found that PPS was becoming increasingly significant, she began to recognise disability. Further, she realised that disability had, from the earliest days, been associated with discrimination, but she had not acknowledged it at a conscious level.

The disabled women, in overall terms, did not tend to look at separate out their lives into component pieces, or compare the different identities (or looking for similarities) within their whole. Rather than comparing and contrasting two identities within the whole, interviewees characteristically preferred to examine one aspect, for example unpaid work, or one identity in a particular setting, for example disability and motherhood. The 'excursions' into of difference are in the context of their whole identity. Interviewees characteristically examined the identity, and its implications in some detail. They may give a number of different

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[70] Tables 67 and 68. Statistics NZ, (1997a).

examples of its presence, as Sophia does when she talks about disability, or Olive about unpaid work.

It is also noticeable that a picture of the interrelationships between different identities within whole identity vary with time. When Sophia was a child, being female meant a great deal. In comparison, when disability became a factor early in childhood, its importance in relation to being female remained a lesser feature: the disability was invisible and the impact seemed minimal. Early in adulthood work became a highly important factor, while being female and the impact of an invisible disability on being female had significance at a lower level. Throughout her life, differing identities had constantly changing interactions. Likewise for Karen, disability had initial central influence. It became a less significant identity than being female in adolescence and later was joined by work, which fluctuated in importance, and racism.

To attempt to capture and codify these relationships between identities is not, ultimately as important as recognising the sense of wholeness and fluidity that pervaded the narratives. Any of the narratives highlights contradictions, tensions and difficulties associated with one identity that is part of any individual overall identity. For example, Karen might identify the disablism and bullying of her schoolmates, or the difficulties of finding paid work as a single and pregnant woman, or how racism impinges when her son is told he is a dirty Maori. But Karen's narrative is not about these identities as disjointed aspects of a life, sometimes overlapping. Rather it is about how aspects of tension or difficulty become evident at different points, but are part of a whole.

Discussion

The ongoing changes to interrelationships of identities within an individual, their fluid nature, are the key points to recognise. The changing combinations of identity pose strong questions for theoretical constructions of identity in which stasis is a

feature. Disabled women do not, in these narratives, define or identify themselves in relation to any one identity, even though one identity may be highly significant. Tierney (1993) relates the words of Robert Sunchild who has, like these disabled women, a number of different identities. However, he rejects easy or linear classifications, saying: " 'People want to define me' he said. 'I'm me, all of me, and most people don't want to see that' " (1993: 131).

Bhabha's (1993) description of multiple identities is consistent with this. He says identity is:

> A scenario or circulation of meanings, and values and positions, identity as being an illusion of totality, and yet within that illusion, that ambivalence within identity can be strategically, historically, socially deployed. (1993: 192).

He goes on to describe the possibilities of such an "interstitial" or in between space, saying it is may be possible to "subvert authority" by "using these ambivalences and ambiguities" (ibid: 190).

In saying this he does not imply that the women might, on reading their narratives become suddenly changed in a revolutionary manner, Rather he describes how, by applying the concept of multiple identities, and applying it to reading narratives or other such descriptions of marginalised people, the contradictions, gaps and paradoxes of the dominant discourses of disability can be seen. The distance between anyone of these life narratives and stereotypes of dependency, and helplessness is considerable and visible. In short, the narratives, and the sense of wholeness to the lives implies change.

Although I have drawn out common themes from the narratives in this section, there remains a strong sense of lives lived whole that is not extinguished in the exercise of analysis. It is this final, 'all together' that is not described by examples.

The environment does not encourage the women to be whole, but they are and on their own terms.

CONCLUSION

This research project began with the key purpose of developing ways to show the experience of being disabled, female and older at one and the same time- the experience of multiple identities that Bhabha (1994) calls 'in between'. It also derived from my commitment to, and membership of the community of disabled women, and the knowledge that we are, as a community, absent in any real way from public record. This then led to a decision that I would audiotape life stories of older women with disabilities. The project would enquire what had been the experiences of these women, and it would be the start of an archive of audiotaped material that disabled women could access.

In this thesis I have described the steps I took in the project, beginning with the theoretical basis that informed it then moving to methodology, information gathered from the interviews, and discussion of the content. Here I review the project, and evaluate the extent to which it succeeded on its own terms.

The life stories show that there is substantial dissimilarity between the experiences of the disabled women and the conventional images of disability. From recording of life stories of older women with disabilities, and analysis of the interviews the research project adds to existing critique of dominant discourses about disability. More specifically, it suggests that the discourse is even more inaccurate and harmful in providing a basis for law policy and practice than had previously been described, since its tangible consequences for disabled women, where there is more than one identity, is shamefully inadequate. The information in the life stories is consistent with the growing body of literature, both in this country (Munford, 1997, Ballard, 1994, Boyles, 1995) and internationally (Gadacz, 1994, McNabb 1992, Morris 1991, 1996, Oliver 1996) that challenges dominant definitions of disability or details a range of inimical effects of the definitions.

The attitudes and effects recorded in individual interviews and in relation to widely varying circumstances are a reminder that stereotypes of disability have had impact at more than one single level. Not only has the impact been on law, regulations or policy, which could be viewed as 'up there', but also the impact has been at an everyday level. There has been individual discrimination as well as discriminatory policy. The material in the interviews is very consistent with Foucault's description of power and its manifestation as something that occurs in everyday interactions in ordinary settings, rather than something that comes from the top down.

Themes emerging from the interviews have a number of similarities with the themes of the literature. There are three, related ways in which this consistency is particularly noticeable.

The first is seen in the way disability constitutes an 'absent presence'. In written and visual material, images of disability are delineated in negative terms, and have come from sources external to disabled people. Disabled writers, for example Vernon (1996), have vigorously asserted that the stereotypes formed from the outside do not fit with the lived experience of disabled people. But while disabled people were (are) not a party to forming the ill-fitting images, they need to live with their consequences.

The experiences of the disabled women I interviewed reflected this paradoxical situation. They did not describe their lives in terms of passivity or helplessness, although they were well aware of the negative images. Neither did they deny that disability was part of their lives. Rather they repudiated the images through the way they dealt with the effects. The women with disabilities here often ignored or avoided the effects, or being identified with the images. They chose instead to 'pass' as non-disabled in employment, chose not to hear questions about their disability that they considered intrusive, or find obsessive activities to absorb the

anger engendered by discrimination. The effect was that disability was, at the same time, present and absent in their lives. While disability was a significant component of their identity, it was avoided or ignored, and this may well be because it was presented as such a negative, disvalued entity.

The second way in which literature and interviews are similar relates to the first. Both highlight that the way identities that make up an individual's overall identity relate to one another is disjointed. Research suggests that disability, gender age and work relate one to another to differing extents, and in different ways, depending on the particular issue. For example, caring raises similar kinds of concerns for old people and disabled people, and it is an issue of concern to women. But the concern from a perspective of gender appears to be very different from the perspective of disability, so that the different identities can be seen to have conflicting interests.

In the interviews, linkages between different identities were also disjointed. The disabled women tended to pick one particular aspect of identity out of the whole and examine it alone, or put two aspects such as age and disability alongside one another, often in contrast: they were often seen to have little in common with each other.

The third similarity, which follows from the second is the absence of an approach to identity which adequately comprehends, and responds to different aspects of identity. In the literature reviewed, a number of writers support an overall identity where one single identity, such as disability (Oliver, 1996) or two dominant influences such as disability and female (Morris 1996) dominate. Others (for example Bhabha 1994, Sawicki 1992) point out that overall identity is more complex than such a description. They argue instead that a variety of identities will fit together in relation to a particular context. Identity is thus still the ground of varied interpretations, and no single view is accepted.

Likewise, the interviews do not give a clear and unequivocal view of identity. There is an overall sense in each life story of a whole individual, within whom are recognisable identities of age, disability and gender. In this whole, no single identity predominates, although at different times within each woman's story, different combinations of identity, such as age and gender can be found.

The growth of appropriate processes and methods of research in this project grew from the literature describing relations of power and the way disability has been conventionally described in thoughts, attitudes and practises. From this background, it became clear that research conducted in a positivist tradition could not adequately address the situation of a marginalised group such as disabled women. For this reason, the methodology was chosen to draw out their experiences in a way which did not disempower them. In doing so it highlighted two features which have considerable implications for research practice: consultation and partnership.

Consultation with the community is a more 'expected' feature of research among some communities than others. It is a regularly incorporated feature of research among Maori, and it is implicit in principles of emancipatory research and in a number of feminist methodologies. But it is neither widely used, nor is it a routine expectation of those who wish to research among marginalised groups. Although other features such as informed consent are a (justifiable) necessity, consultation is not accorded such a status.

I began the project some time before the actual interviews, in ongoing discussion within the community of disabled women. I first inquired whether the project was desired, and a priority for the community. Following these answers, I asked more specifically about the scope of the project, and use of the information. As the project entered a more active phase, I used a reference group of disabled women

with whom I could discuss issues and concerns about the process. Consultation was at all stages of the research a 'given' component.

In one sense, it is understandable why consultation is not undertaken. It raises spectres of an overwhelmingly difficult process, where extra, costly and time-consuming processes are gone through, and key people in the community are identified, then sought. Whatever is done seems to be both insufficient and too difficult. An individual with a small project might well consider that individual consent is sufficient, as they are clear that their intentions are beneficent. And since they are working with individuals, not a whole community, consultation may seem less than relevant. But the unspoken message of this approach is that priorities and interests of the marginalised community are of lesser importance, and there is likely to be little effective change to existing power relations. However, lengthy and difficult consultation, leading to poor outcomes are not an inherent part of the process. Rather, such a result will come when the techniques of consultation are not understood, or are ineffectively used.

The wider question raised by the use of consultation in this project is what it might mean in relation to ethical considerations. In the most general formulation, research ethics are concerned with an absence of harm, an intent to confer benefit. Informed consent is one of the ways in which this intent not to cause harm is put into effect. In this thesis, I have argued that consultation with a marginalised community is necessary, and that its absence can mean the community, as a whole, is disadvantaged. Since consultation similarly conveys an ethical concern not to cause harm, and to convey beneficence to a community, it could reasonably be argued that consultation merits serious consideration as a core component in any ethical processes used in research. I contend that more widespread debate, particularly by ethics committees is needed, since the perception that consultation is 'too hard', or unnecessary is widespread.

Partnership within a research project is, like consultation, less common in mainstream research. To use it in a research project may induce researcher anxiety, since there are many factors for which a researcher must bear responsibility, and partnership appears to hinder this. Since the desires of the researcher, and the requirements of a sponsoring or overseeing body may not be the same, negotiation or compromise is likely. To add a third 'body' whose requirements and interests may be different again from either party, but which needs to be negotiated-with can seem too difficult an obstacle.

As I have argued for a positive appreciation of consultation, I also argue that the use of partnership approaches are beneficial and more ethically responsible. Difficulties for the researcher in operationalising partnership should not override the requirements of participants for a fair process. In practice, I found that a fair and open approach, and trust in each other's honesty, and a mutual commitment made the process unproblematic. Being an insider in research may make trust come more readily, but a shared identity does not mean an automatic exemption from honesty and sharing, and the processes which maintain a partnership approach.

A partnership process does make demands of both parties. It requires levels of trust, and of rigour that neither party may have anticipated. To give a summary or an analysis to the individual about whom it is written is a challenge to openness. The response can be about "that's not what I said" in addition to the "that's not clear" response of conventional research. Further, in conventional research, subjects tend not to 'talk back', or critique the research. Debate may be as rigorous as from any conventional supervisory bodies. Similarly, the recipient is reading a view from the outside of the life they have lived from the inside, and another's analysis can be disconcerting, even discordant. The process of partnership is not easy. But to have recorded life stories and not to closely involve

the people whose life was being told would, I contend, not be an adequate process.

In this research project, interview and information processes were designed to be accessible. While this term is not widely recognised within mainstream research, it has implications for any research which deals with marginalised groups. Here, 'accessible' means that the process automatically adapts to the requirements of disability. If people do not have information in a form they can use, they cannot participate on equal terms, and unequal power relationships are perpetuated. Without this participation, partnership, or informed consent are more illusory than real. That the project was accessible was one of its strengths.

I started from a baseline that information would be available in the format of choice, as a matter of course. I also ensured that I, as researcher, actively solicited preferences. It cannot be assumed that all blind people will require braille, or that all people who are print disabled will require tapes. I assumed, as a matter of course, and consistent with the principle of equity, that having information available in accessible formats did not constitute a 'special' accommodation; it was a routine process that enabled participation of all involved parties.

One question that arises from this project is how identity for disabled women can be adequately understood. I have suggested that recognition of the differing components of overall identity-'me, all of me'-and in terms of changing components according to the circumstances is most useful. It has greater descriptive power than the approach of the dominant discourse. It is more flexible, and is inclusive of diversity. Its further advantage is its ready use as an instrument of change to established power structures (Bhabha, 1994, Hicks, 1988). The disadvantage of the approach is that it constitutes challenge to the concrete consequences of the dominant discourse, and challenge or possible change to thoughts, attitudes, language, laws, policies and practises is not usually welcome.

The approach I have suggested needs further debate as it's fit with the experiences of disabled women in this project is not absolute. The debate is one potential outcome of the thesis.

Also arising from the research is the issue of who is an appropriate person to perform research. I have articulated elsewhere (Wicks and Terrell, 1992) that the most appropriate people to research in a marginalised community are usually members of that community, though I have also pointed to the value of allies. I have also pointed out that control of the process by disabled people (women) at all stages is of equal importance. It is through greater control of the research process that change can be more readily effected. But the difficulty lies in access to that control for disabled people. In the present climate of social science research in Aotearoa/New Zealand, access to funding for independent research is very difficult, and contract research is largely within parameters decided by the body providing funding.

It may appear that this research project has said little that is definitive about identity for disabled women. But the research did not aim to provide definitions- it rather aimed to illustrate experiences. And within those terms it has had some success. First, the research has served to highlight more clearly the limitations of approaches that are based on external perceptions of identity rather than internal experiences. Likewise of limited value are the additive approaches where, for example, disability is added to gender. Second the methodology that has been delineated, then operationalised has worked well, and has shown that very different relations of power in research production can be achieved. Third, the actual creation of a record of the lives and experiences of disabled women has begun a process away from silence. Disabled women have begun to tell one another, and others about their lives.

I began this thesis with Karl Marx's assertion that description leading to change, is a better direction for academic effort than description alone. In my research project, I aimed to facilitate change, through bringing together for the first time the life stories of disabled women, and through a process that was appropriate to the community. I did not attempt to prescribe the nature of the change(s). The community of disabled women, and particularly the disabled women I interviewed, will determine what form the changes will take.

Although the research project has had no definitive outcome(s),I am nevertheless confident that the project has served a useful, if Pandora-like function. It has brought previously-unknown material 'out of the box' for the use of disabled women. In its own terms, as a tool that can be used for positive changes for disabled women, the stories are a gift to us all.

APPENDICES AND BIBLIOGRAPHY

APPENDIX ONE

PROJECT ON OLDER WOMEN WITH DISABILITIES

Background Information

Researcher: Wendi Wicks, 3/17 Naughton Tce, Wellington (04) 387-7260 (ph, fx)

Supervisors Ruth Anderson, Department of Social Policy and Social Work,

Massey University (06) 350-5217 (ph), (06) 350-5681 (fx)

Marg Gilling, BERL, 108 The Terrace, Wellington (04) 470-5560

(ph) or (04) 473-3276 (fx)

This project aims to interview older women with disabilities, and to hear from them about their life experiences, particularly in relation to work. The project was started because there has not been a systematic collection of the individual stories of women with disabilities, as told by themselves.

The researcher, Wendi Wicks, is a woman with acquired disabilities. She is doing the research as part of a thesis for her master's in social work (MSW) through Massey University (Department of Social Policy and Social Work), on women with disabilities. Her supervisors for this thesis are Ruth Anderson and Marg Gilling. Wendi also has a reference group of several women with disabilities, who will provide her with independent expertise through feedback on the research, and additional input on relevant matters such as ethical issues. The reference group does not have any supervisory role, and will not have access to participants, or to interview material.

The research will take the form of an audiotaped oral history interview. This is a method that suits the situation well, since women with disabilities can respond to topic areas in their own words and retain much control over the process. Women who agree to participate in an oral history interview will be named on the tape(s), thus affirming their ownership of their own life story.

Women with disabilities who agree to participate in an oral history interview will be asked to provide formal consent to their participation (including audiotaping)

following face-to-face discussion of the research process with the researcher. Questions from women with disabilities about the study, and about their participation are welcomed at any stage in the research.

Women with disabilities have the right to decide they will not participate in the research process. They have the right to decline to answer any particular question, and have the right to withdraw from the process at any point.

The oral history interview will be audiotaped, taking between one and three hours to complete. It will take place in a setting agreed to by each participant and the researcher. A transcript of the recording will be made, and if this is done by an individual other than the interviewer, that individual will sign a confidentiality agreement.

After the interview is completed, the participant will be invited to give her consent to file copies of the interview tapes and transcripts are deposited with the Oral History Archive at the Alexander Turnbull Library.

Following the interview, the researcher will present a transcript of the tape in accessible format to the participant, discuss this with the individual, and answer questions, so that accuracy can be checked.

A copy of the taped interview, and an accessible format hard copy of the transcript will be given to each participant. Participants will also be given a summary of findings of the study after its conclusion.

Wendi is happy to answer any questions and discuss ideas you may have about the project. Should you have any further concerns, or wish for support you may wish to contact the following agencies: Catholic Social Services, Presbyterian Support Services, or Anglican Social Services.

APPENDIX TWO

PROJECT ON OLDER WOMEN WITH DISABILITIES

Consent to participate in oral history interview

Following the receipt of written information, and discussions with Wendi Wicks, (ph and fx 04-387-7260) I understand that:

- The purpose of this research is to record the experiences of a number of older women with disabilities particularly in relation to work.

- The interviews will contribute to the completion of an MSW degree by Wendi Wicks and any associated research papers and publications.

- The research project will be supervised by Ruth Anderson of Massey University(phone 06-350-5217, fax 06-350-5681), and Marg Gilling of BERL (phone 04-470-5560, fax 04- 473-3276).

- Wendi will have input from an independent reference group of women with disabilities. This group provides a perspective of women with disabilities for the research project, but members of the group will not have access to the interview material or to participants.

- The setting for the interview will be mutually agreed, will meet my requirements for accessibility and communication, and ensure privacy.

- The oral history interview will be audio taped, and will take between 1 and 3 hours, as required and mutually agreed. In the interview, I will respond to topics in my own words.

- I have the right to ask questions about the research project at any time.

- My name will be recorded on the audiotape(s).

- I have the right to ask for the tape to be turned off at any time during the interview

- I have the right, at any point and for any reason, to withdraw my participation in the interview.

- I will view and/or hear full transcripts or tapes of the interview in which I participate. I will also receive a personal copy of this interview and transcript in accessible format.
- When the interview is completed, I will be invited to release the interview for use as above by signing a recording agreement form. By signing this agreement, I will also agree to deposit of the audiotaped interview, and transcript at the Oral History Archive in the Alexander Turnbull Library.
- Only tapes which have been subject to my signing the recording agreement form will be used in the research project. Other interview material will not be used, but will be disposed of in a secure manner that is consistent with the 1993 Privacy Act.

On this basis, I agree/ do not agree to take part in an audiotaped oral history interview.

Participant... Date:.........................

Interviewer... Date:.........................

APPENDIX THREE

PROJECT ON OLDER WOMEN WITH DISABILITIES

Oral History Recording Agreement Form

Name of Person interviewed:

Address:

Date and place of interview:

Interviewer:

Overseeing Body: Department of Social Policy and Social Work, Massey University

1. Placement: I agree that the recording/s of my interview and accompanying material will be held at the Oral History Archives of the Alexander Turnbull Library.

2. Access: I agree that the recording of my interview and accompanying material may be made available to, and/or copies supplied to, bona fide researchers, OR I wish for conditions of restricted access to apply to the materials detailed in the following section.

See also section 6.

3. Restricted Tapes and Accompanying Material

I require that there will be no public access to or use of the following numbered tapes and accompanying material before the release date indicated **without my prior formal consent in an appropriate format**.

Tape Number   Review/Release date

4. Public Use   : I agree that the recordings of my interview and accompanying material may be quoted in published or academic work, in full or in part, subject to any restrictions in section 3 above.

5. Privacy Act: I understand that this agreement form does not affect my rights under the Privacy Act 1993.

6. Identification: I do not wish personal identifying details such as my name to appear in any published use of the interview. Please specify below:

Person Interviewed: **Date:**

Interviewer: **Date:**

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NEW ZEALAND LEGISLATION

Mental Defectives Act	1911
Disabled Persons Employment Promotion Act	1960
Equal Pay Act	1972
Accident Compensation Act	1972
Disabled Persons Community Welfare Act	1975
Human Rights Commission Act	1977
Contraception, Sterilisation and Abortion Act	1978
Human Rights Act	1993