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**DISCOURSES AND NARRATIVES OF DIFFERENCE: 'RACE', RURALITY
AND ILLNESS
THE CASE OF THE HOKIANGA, NEW ZEALAND.**

Helen Bromley

A thesis submitted to the University of Bristol in accordance with the requirements
of the degree of PhD. in the Faculty of Social Science.

Department of Geography

September 1998

ABSTRACT.

In this thesis I explore ideas of health, 'race' and place in one rural area of Aotearoa/New Zealand. Drawing on the theory and methods of social science, I examine how notions of 'discourse', 'otherness' and 'the body' are played out in the health field. Investigating the entangled discourses of otherness, 'race'/ethnicity, disease, and rurality exposes the processes whereby disease becomes 'racialised'. In analysing different constructions and interpretations of health amongst Maori and Pakeha people in the Hokianga, I also show how marginalised groups negotiate their everyday health concerns. I do this with specific reference to the practices and experiences of chronic disability, and the provision of a home help service in the Hokianga. Using home help as a vehicle, I then go on to examine some of the wider significant issues uncovered by this approach: how marginalised groups, and their marginalised representations and experiences of health and the body, are intimately connected to notions of gender, age, 'race'/ethnicity and rurality.

The thesis also addresses what I consider to be three major tensions within the current field of social science. These are the gap between academics and policy makers in both theory and practice; the necessity for contextualised theory to accommodate the particular circumstances of different regions - place matters; and that the politics of research constantly remind us of the tensions involved in issues of representation and of 'speaking for others'.

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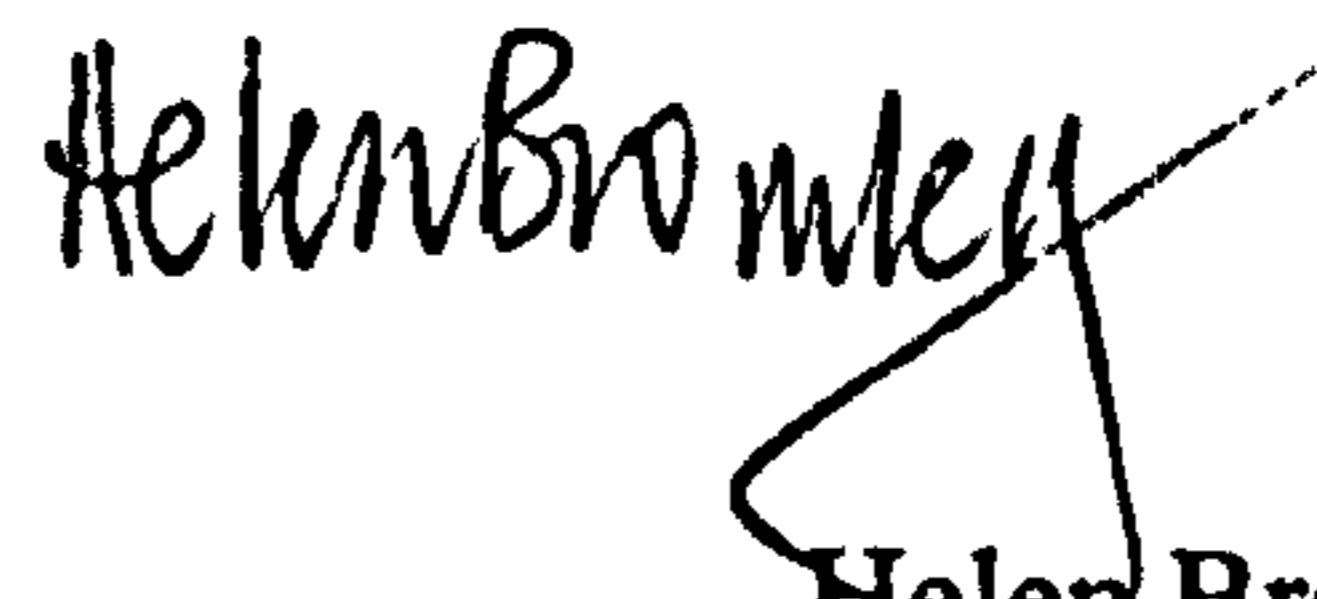
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AUTHOR'S DECLARATION AND DISCLAIMER.

I declare that the work in this thesis is entirely my own work. All views expressed in this thesis are my own, and in no way should be taken to represent the views or opinions of the University of Bristol.

A handwritten signature in black ink that reads "Helen Bromley". The signature is written in a cursive style with a large, sweeping flourish at the end.

Helen Bromley

September 1998

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PREFACE.

I have always been fascinated by the diverse ways in which people deal with, and make sense of illness. How and why these differ at global, regional and local scales is a constant source of interest to me. Basically I am interested in different cultures and their numerous health beliefs and customs. I believe their importance cannot be overlooked, because of the vast amount of time and effort spent on maintaining good health in all societies. Moreover, the sheer diversity of ways in which health is maintained, and illness treated, is enough to make it an important subject for study. In particular, I am interested in medicine *as* culture, rather than medicine and culture being two discrete entities. These preoccupations stem from my own experiences as a nurse and as a student of social science. Traditionally, western biomedicine has not been seen as a part or product of culture, but as an objective body of scientific knowledge, somehow outside or external to culture. I want to argue that health issues are so deeply embedded in their relevant culture, that the two are not separable, as is often assumed to be the case. We construct our understandings of the world, including our beliefs about health and illness from our social interactions with culture and cultural products, as well as from personal experiences and the stories of others. Because of this, culture and health are inexorably intertwined. Good, or bad health is a culturally dependent issue: as such, any related study should contextualise its research material, including not only assessments of specific diseases or health problems, for example, but also an appraisal of the social and cultural milieu in which they occur.

Although a biomedical approach has advantages in certain situations, its 'neutral' explanations render understandings, explanations and experiences of being ill as an asocial event. Medical issues are deeply embedded in culture and society, they do not take place in a vacuum. I therefore believe it is necessary to make room for the social in our explanations of health and sickness. Social factors are of critical importance in illness and death, and because biomedicine cannot account for these, new theoretical approaches are needed. They must acknowledge the importance of behaviour and lifestyles as well as recognise the chance interlinking of social, political and economic factors. This could bring a different perspective to culturally marginalised groups' health problems as they themselves see them. We cannot divorce medicine from culture or society, so it is important to at least appraise the value of contemporary theoretical developments.

This thesis is therefore an examination of the social world of illness, and is situated within the social, cultural, political and economic context within which this occurs. It involves a consistent interrogation of things abstract to things practical, in an attempt to ingrate social theories into the real lives and experiences of the people who participated in the project. In the thesis, I explore what is socially and culturally different for marginalised sections of the population that exacerbates certain types of health problems. I focus on geographies of social exclusion and what impacts these might have on health status.

The aims of this study are to (i) extend the medical geography tradition by examining wider political and social forces in the production of ill health; (ii)

to bring some contemporary theoretical debates in human geography to medical geography; (iii) to reconceptualise medical geography in three ways. These are a paring down of the scale of studies; becoming more aware of our situated position in the construction of texts; and to bring in other voices in that construction. I hope this will extend our understandings of the social-cultural dimensions of health.

In the thesis, I illustrate these ideas with practical work carried out in New Zealand. The focus is on the interweaving of place, physical impairment, and the marginalised place of rural health research. I ask whether there are different health discourses and practices amongst different groups and to what extent (if at all) they are implicated in the geographies of exclusion. By analysing the constructions and interpretations of different discourses of health amongst Maori and Pakeha people, I hope to examine the material linkages between social political and economic relations and health as evidenced in lay opinions and narratives of illness and disability. This should allow me to analyse the consequences of hegemonic discursive constructions of health in two ways. Firstly, how they affect marginalised groups; and secondly, how they affect marginalised representations of the body.

Chapters 1 and 2 are 'terrain' chapters. In them I explore foundational geographies in both discursive and practical ways. In Chapter 1, I outline our understandings of illness from biomedical and social constructivist viewpoints. I then consider medical geography as a framework for understanding disease. In Chapter 2, I build on Chapter 1, by exploring alternative literatures I believe important for health geographers. In Chapters 3 and 4, I elaborate on these ideas

but from a more practical perspective. Chapter 3 considers social, political and economic factors that are currently influencing health and health care in New Zealand. In Chapter 4 I examine New Zealand rurality and rural health, and introduce the Hokianga as a case study. Research like this is not necessarily representative of New Zealand at large, but I accept this at the outset. I end the chapter by reflecting on the nature and politics of undertaking research in an unfamiliar area, giving examples of my own experiences in the Hokianga. Chapter 5 contains the research methods used to conduct the study. In it I also describe some of the shortcomings of the methodology and the study design.

Chapters 6, 7, and 8 contain the empirical work of the thesis. In Chapter 7, I begin to think through issues of 'race'/ethnicity rurality and illness, and try to untangle some of the ways in which they impact on each other. Chapter 7 is more tightly focused. In it I discuss the ways in which home help in the Hokianga constitutes an important component of a person's identity, by encompassing issues of social support and cultural sensitivity. Chapter 8 takes stories of home help experience and integrates them into a wider examination of the body. In particular, I concentrate on discourse of the body in terms of gender, 'race'/ethnicity and illness, disability and death. Taken together, these chapters document some of the medical and cultural geographies of marginalisation and exclusion. In Chapter 9, I conclude that a community focus is a useful approach to health issues, because there is no one solution to health problems; they are localised, contextualised and highly contingent on many other factors.

MAP 1. AOTEAROA/NEW ZEALAND.



CHAPTER 1. A PICTURE OF HEALTH.

1.1. INTRODUCTION.

In February 1996 I attended the Third Asia and Pacific Conference on the Social Sciences and Medicine. The theme of the conference was partnerships in health and social science. For various reasons, I have vivid memories of two of the sessions I attended. The first was called 'Researching Health Policy in the Asia and Pacific Region: Context and Content'. It included a paper that examined the implications of poststructuralism for health policy. My overarching memory of this session was that the vast majority of people attending, social scientists and medics alike, had absolutely no idea what poststructuralism was. A Pakistani delegate's comment also sticks in my mind:

"Why are we debating the merits of French social theory, when my people are dying from disease and famine? We don't need theory, we need food, antibiotics and vaccines".

The second session I attended was entitled 'Research and Planning for the Advancement of the Health of Indigenous People and Minority Groups in the Asia Pacific Region'. I had written a paper for this session, at least in part to get funding to attend the conference. Bearing in mind I was writing for an international audience, who were (I assumed) probably unfamiliar with New Zealand issues, it was pitched at a fairly general level. The paper (written only two months after arriving in New Zealand) took a brief look at the situation there. Declaring my recent arrival and taking an avowedly non-expert stance, the paper was divided into four sections; (i) health issues facing Maori (ii) Maori conceptions of health (iii) national and regional strategies for improving Maori

health status (iv) the Hokianga area as a case study. The papers submitted for this session were not formally presented, but were distributed to the participants of that session for perusal in their own time. The following day, two Maori delegates approached me and made me withdraw the paper from the (soon to be published) conference proceedings, telling me in no uncertain terms to “stick to white communities” whilst in New Zealand.

These events made a deep impression on me, not only because of the distressing nature of the encounter mentioned above. In my opinion, they also exemplify some of the most acute dilemmas facing contemporary social research. These are (i) a gap between academics and policy makers in both theory and practice; (ii) a need for contextualised theory to accommodate the particular circumstances of different regions - place matters; and (iii) that the politics of research constantly remind us of the tensions involved in issues of representation and of ‘speaking for Others’; that is the ways in which we present our work and talk about those who constitute its subject matter. These three dilemmas form part of the backdrop for this thesis. In it I explore, develop and extend these issues in order to contribute to the debates in which they are entangled.

I am interested in examining these debates as they apply to health matters because I am primarily interested in the geographies of health. As a point of departure, therefore, this chapter outlines current ways of conceptualising health and ill-health. It is divided into several parts. The first section examines some of the dominant conceptions of health and ill-health. This is a tortuous, vexed and contentious issue, although in terms of policy and planning

perspectives, a crucial one. In the second part I consider the current dominant model of health and what the implications and criticisms of this configuration are. Following this, I explore an alternative approach to understanding health, assessing the utility of it when considered in the light of dominant conceptions of disease. This leads on to how medical geography adds to this as (part of) a framework for understanding health. The chapter then appraises emerging directions within medical geography, and considers their implications. In closing I conclude that current conceptualisations of health and ill-health are inadequate, largely because of their a-contextual nature. I suggest that one way of remedying this might be to theorise more broadly about health matters; that is by drawing on a wider theoretical background than is usual in mainstream medical studies. This may pave the way for more thoroughly contextualised and grounded ways of thinking about health and ill-health.

1.2. CONCEPTUALISING AND DEFINING HEALTH.

All cultures¹ have words for health and well being, and yet there are still ongoing efforts to define what health really is, and what it means to us (Hart 1985; Lee 1982). From concepts of harmony and equilibrium, to notions of it as

¹Raymond Williams describes culture as ‘one of the two or three most complicated words in the English language’ (1988: 87) and I use it here as an umbrella term for a particular way of life. Culture is ‘contested, temporal and emergent’ (Clifford 1986: 19) therefore it is time and place specific. In the context of this study, culture is used in its broadest meaning to define a whole range of practices that structure everyday life, so that ‘taken in its widest ethnographic sense, it is that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capabilities and habits acquired by man [sic] as a member of society’ (Asad 1986: 141).

a commodity, or as a discourse (Fox 1993), health has become a word and a concept, that is often used unproblematically. Part of the difficulty lies in the fact that conceptions of health and illness vary between societies, as well as among different groups within a single society, and in any single society over time (Townsend and Davidson 1982: 34). As a result, conceptions of health are continuously changing and evolving, adapting, and undergoing revision. Because of this, what can be seen as an essentially subjective and personal knowledge (we all know what feeling ill or healthy is like) becomes extremely difficult to convert into a standard definition or measure (Hart 1985: 2).

Definitions of health have varied over time and space, often reflecting predominant diseases or causes of ill-health at that instance. In Victorian Britain for example, health was conceived in terms of (the absence of) tuberculosis, diphtheria, measles, smallpox and many other acute infectious diseases. Between roughly 1850 and 1950, however, Britain witnessed a steep decline of many of these infections, and a steady increase in other mainly chronic and non-infectious conditions, such as arthritis, cancer and ischaemic heart disease (McKeown 1976). Definitions of disease and health have changed accordingly, so that health has now become conceptualised in terms of morbidity, rather than in terms of mortality as it had been in the nineteenth century². Today, there are many different types of health definitions. They range from 'not merely the absence of disease and infirmity but complete physical, mental and social

²The mortality rate is defined as the ratio of the total number of deaths to the total population, whereas the morbidity rate is the amount of sickness in a population.

well-being'³, to 'health as a resource for daily living'⁴. The 1948 World Health Organisation's definition emphasises the individuals' perspective and their psychological state, and could therefore be classed as a perceptual definition. Functional descriptions of health comment on the ability to perform everyday tasks and are dependent on one's place in society. 'Health as a resource for daily living' would fit this category, transforming a concept of soundness into the responsibility of the individual. There are also normative definitions of health which refer to the degree of conformity within the basic conditions of age, sex and region, for example, that is the average value for the population under consideration. Normative definitions tend to be used by health professionals and have also been used by the World Health Organisation in the past (Aggleton 1990: 9).

Defining health is problematic partly because we have so many different words for it. Kleinman (1988), in his book on chronic ill-health, distinguishes between disease, sickness, and illness. For Kleinman, disease is 'what the practitioner creates in the recasting of illness in terms of theories of disorder. It is the problem seen from the practitioner's perspective' (p. 5). Illness on the other hand is 'how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability' (p. 3). Sickness is defined as 'the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces'

³World Health Organization 1948.

⁴Epp Report 1986.

(ibid.). There are thus differing notions of what it means to be healthy or ill within and between societies.

Western societies' ideas about health and disease today are structured largely by medical scientists and the media. Through scientific approaches, the medical world is seen by most as an objective, rational and scientific arena in which medical advances occur. The world of medicine is the world of the microscope, the gene and most recently, cloning⁵. These representations are produced and reproduced through newspapers and television, where medicine is portrayed as helping humanity - albeit mostly at a cellular or sub-cellular level. Medical discourses, where language and jargon is rife, further perpetuate this condition, serving to mystify those who are excluded from those elite circles who are 'in the know'. But medicine has not always been in such a position of power. Prior to the mid-nineteenth century, healers were seen as quacks and sometimes even as witches (Ehrenreich 1974; McNeill 1976; Nikiforuk 1992; Starr 1982). In addition, Foucault (1976) has traced the links between certain medical discourses and the exercise of power in society, that is the development of alliances between discourse, practice and professional groups (see also Armstrong 1983; Fox 1993; Lupton 1994, 1995; Turner 1995). These works and others, show that medicine and medical issues are time and place specific; they are context dependent. This is important because it reminds us that medicine is not necessarily a static enterprise, but can (and ought to) be open to criticism and change. This point, coupled with the fact that in many cases, biomedicine has failed to relieve suffering, forms a starting point for my thesis. The following

⁵For an interesting and critical overview, see Lewontin 1991.

section details the historical development of the biomedical model and the main premises on which it is based; in the ensuing sections I develop a critique of this position and consider alternatives.

The medical model, biomedicine and its critics.

In the case of western culture, the hegemonic definition of disease is the biomedical one. This model emphasises positivism, biology, individuals, intervention, technology and specialism (Jones and Moon 1987: 349-350). In the western world, our ideas about health and healing are often cited as originating from Greek mythology (Jones and Moon 1987; Renaud 1993; Townsend and Davidson 1982). Asclepios (the god of medicine) was an expert in medical intervention, cure and the external control of sickness. He was eventually struck by thunder for trying to resurrect the dead in exchange for a large sum of money. Asclepios had two daughters: Panakeia was a true healing goddess, who would cure people by using drugs made from the earth, or plants. Her sister, Hygeia, was the goddess of health, who promoted internal control, nurture and continued well being through the moderation of all things. For Hygeia, health was the natural order of things. Whilst Asclepios and Panakeia have always overshadowed Hygeia, by the mid-twentieth century they had completely eclipsed her. The outcome of this is that the contemporary understanding of health (or rather ill-health) in western culture revolves around intervention and cure. Doctors deal primarily with disease, not with the promotion of health in any positive way; biomedicine and drugs are often considered the 'natural' and common-sensical ways to stay healthy. Much of our biological knowledge was developed during a time when Cartesian philosophy was at its peak and this is

reflected in the taxonomy and mind-body dualism of medicine. Medical knowledge was to be gained not from the patient, but from laboratories, as organs, tissues and cells became the units of study. Today, the biomedical model is the hegemonic way of explaining why and how people become sick. Biomedical knowledge sees disease as biological fact (Jones and Moon 1987: 4), where a cause leads to a lesion which produces a symptom. This is a one way cause and effect model (White 1981). It is linear with no feedback looping; as such, it could be described as modernistic.

There are four key assumptions underlying the biomedical model. They are: the definition of disease as deviation from normal biological functioning; the doctrine of specific aetiology; the conception of generic diseases (that is a universality of disease taxonomy); and the scientific neutrality of medicine (Freidson 1970; Illich 1976; Mishler 1981; Navarro 1978, 1982, 1986). The perspective that disease is a deviation from normal biological functioning dominates medical thinking at present, although it is problematic for several reasons. The ambiguity of the word normal, for example, raises the question of what is normal - and for whom? Against what standard should it be measured? Who sets the standard against which it should be measured? Norms are socially and culturally constructed and negotiated, they are not automatically given (Parr 1998). The word tends to be used vaguely in both medical and lay parlance, and there is often confusion over whether 'normal' refers to an ideal standard or to an average value. This means that quite often, we are not really sure what is normal and what is not and this creates all sorts of problems when trying to define disease. Although deviation from the 'norm' is the current hegemonic definition of disease, other definitions have been used, for example the Platonic

model where health is seen as harmony among the body's structures and processes, or the Galenian approach where disease is caused by a disturbance in function. These broader definitions are not only of historical value, or even obsolete, because they are still used by the World Health Organisation and others when analysing health and disease issues today. Moreover, the broader the definition of health or the view of disease, the '...easier it is to recognise the significance of cultural, psychological and social factors which are the substance of the social and behavioural sciences' (Mishler 1981: 4).

The second assumption of biomedicine is based on the doctrine of specific aetiology. This is a more specific assumption than the first and postulates that there are definite causes for definite diseases. The idea of a cause and effect model developed out of the work of Pasteur and Koch who showed that specific diseases could be produced by the introduction of specific virulent micro-organisms into the body in the late twentieth century (Mishler 1981: 7). Because death rates were decreasing at this time, the idea of specific aetiology (also known as germ theory,) took hold in the medical imagination as the prime reason for the decline. By the middle years of the twentieth century, the doctrine of specific aetiology had spread from infectious diseases to chronic and non-infectious ones, often giving explanations that were oversimplifications of complex biological and social processes. However, since the 1970s, the notion of specific aetiology has been widely disputed and come under sustained attack. The convincing works of McKeown (1976) and McNeill (1976), for example, have shown how the declining death rate at the end of the nineteenth century was nothing to do with the knowledge of specific aetiology. It was actually brought about by measures in public health and an increased standard of living

as opposed to specific disease interventions. Moreover, this decline was well under way before the advent of germ theory. This evidence considerably reduces the claim of biomedicine to have cured most of our ailments in the nineteenth and twentieth centuries.

The third tenet of biomedicine is the conception of generic diseases and the universality of a disease taxonomy. Each disease is assumed to have specific and distinguishing features that are universal to the human species. Conceiving diseases as generic assumes their manifestations and effects will be ubiquitous in vastly different cultures and societies. (Mishler 1981: 9). As a result, the principle of generic diseases does not allow for diverse peoples in different times and places to experience illnesses according to their own conceptions of disease. By this I mean that although the biological processes of disease may be the same, generic conceptions of disease do not allow for different societies' interpretations of that disease. As a result, western biomedical explanations remain the only legitimate account of disease origins and causes.

The final principle that underpins biomedical thought is that medicine is scientific and neutral. The rationality and impartiality of scientific methods, their objectivity and neutrality characterise much contemporary medical research and judgement. This gives the impression that the work of doctors as practitioners is guided primarily by 'objective' scientific rules and criteria and remains relatively unaffected by wider social, cultural and political forces (Mishler 1981: 16). But medicine, far from being independent of society, is deeply embedded within it and therefore cannot remain neutral (Lupton 1994; Jones and Moon 1987). Yet it is precisely this embodiment that it tries to eschew.

In summary, biomedicine remains the dominant model of disease today. It assumes disease is fully accounted for by derivations from the norm of measurable biological (somatic) variables. Moreover, because the basic scientific discipline underpinning it is molecular biology, no room is left for the social, psychological and behavioural dimensions of illness. Gillett has argued that the biomedical model is:

“...reductive and works most comfortably where there is a biochemical and/or structural defect that provides a simple key to understanding the disease being studied. It therefore tries to find such an entity or a surveyable and fairly small set of entities for every disease” (1994: 1127).

If anything, health research has become ever more concerned with the intricacies of molecular biology, instead of taking a step back to look at the big picture. Whilst not denying that molecular and cellular studies are important, it does mean that the critical role of social science in clinical medicine remains marginalised. Cellular studies on the other hand have gained ascendancy in the hierarchy of medical research, collecting both fame and funding. It is often argued that the reasons for this lie in the power of the medical profession as an agent of social control, where the medical profession is implicated in promoting the existing order of society (Ehrenreich and Ehrenreich 1978; Jones and Moon 1987: 6; Turner 1987 Ch. 7 and 8). This is not done as an active conspiracy, but by the very ideas and practices of medicine. And whether one agrees or disagrees with this assertion, it cannot be denied that the social sciences are regarded as less important than the ‘hard’ sciences in health research.

Although biomedicine remains the dominant health discourse, it has not been without its critics. The criticisms levelled at biomedicine are wide-ranging

and potentially far reaching in their implications. Broadly speaking, the most penetrating assessments have come from three disciplinary directions: the viewpoint of 'radical' doctors; the philosophical/theological viewpoint, and the sociological perspective. One of the earliest critics of biomedicine was Rene Dubos, whose book *The Mirage of Health* was first published in 1959. Himself an eminent microbiologist, Dubos's argument consisted of four main themes. Firstly, that it was a myth that the decrease in the death rate in the last one hundred years had anything to do with laboratory medicine; it was actually due to public health measures. Secondly, that it was a delusion to proclaim the present state of western health the best in the history of the world. Thirdly, that the concept of unifactorial aetiology was mistaken and that infectious and chronic diseases were in fact multifactorial in origin; and lastly, that adaptation was a neglected but key concept. Human beings could adapt to most conditions, but given the ever increasing pace of modern life, they no longer had the time to do so. Dubos was the first person to critically assess the *social* causes of disease, although he stopped short of agreeing that medicine should become involved in political reform.

A second major critic of biomedicine and possibly one more famous than Dubos is Thomas McKeown. McKeown produced a ground breaking study that gave empirical weight to Dubos's argument, arguing that medicine was mistaken in its concentration on internal intervention, and that greater emphasis on external influences and personal behaviour were necessary (1976). McKeown argued that these two influences, external and personal, were the major determinants of ill-health. His work constituted a real advance for three reasons. Firstly, it meticulously analysed time series mortality data which had not been

studied before. In so doing, he could map changes in the death rate due to any specific disease and relate these changes to social events such as nineteenth-century sanitary reforms, or the introduction of antibiotics. The second reason McKeown's work became influential was because of the concomitant developments in the sciences of nutrition and immunology in the 1960s. These provided a linking mechanism in the causal chain relating standards of living to deaths due to infectious disease (Blane 1987: 17). McKeown showed it was the effect of living standards that were primarily responsible for the fall in the British mortality rate, mainly because of better levels of nutrition in the population. Finally, McKeown ranked the various factors that may have accounted for the fall in infectious disease. He concluded that medical intervention was of minor importance, because the largest fall in deaths was well *before* the introduction of immunisation and chemotherapy such as antibiotics. Sanitary reforms were given a medium rating in terms of their importance, as most of the infectious diseases were caused by airborne germs. By a process of elimination, he established that living standards, particularly levels of nutrition were the most important reason for the decline in infectious diseases in the nineteenth century.

From a philosophical and theological standpoint, the name of Ivan Illich stands out as the most influential critic of biomedicine. He argued that medicine has undermined:

“...the human processes and natural capacities by which people respond to experiences such as birth, death, pain, fear, and suffering” (1975, quoted in Hillier 1987: 201-202).

In Illich's view, a person can be healthy only when they have the autonomy to cope with the reality of suffering and death. For Illich, medicine is blatantly dangerous. He terms this iatrogenesis, which is divided into three main arenas - clinical, social and structural. Clinical iatrogenesis involves medical profession/hospital induced problems such as unforeseen complications, or a hospital acquired infection. Illich documents a considerable amount of medical literature devoted to this issue. The second type of iatrogenesis is social, where the medical-industrial complex's role in maintaining a sick society is made apparent. Social iatrogenesis promotes the '...medicalization of life and a technical fix' (1976: 31). Lastly, structural iatrogenesis has created a decrease in our abilities to self-care or develop our own coping strategies, instead, we are increasingly encouraged to rely on medical 'experts'.

From a sociological perspective, the most trenchant critic has been Lesley Doyal (1979). She contends that society is neither industrial nor composed of individuals as McKeown and Illich presume, but is capitalist and consists of social groups and classes. She argues that it is the capitalist nature of society that determines both ill-health and the current nature of medicine. Both Illich and McKeown place the responsibility for health with the individual, but for Doyal, the solution lies with equality of access to medical care and a demystification of medical knowledge. She calls for a fundamental transformation to a new mode of production so that:

“...the demand for a healthier society is, in itself, the demand for a radically different socio-economic order”. (Doyal 1979, quoted in Jones and Moon 1987: 30).

Although most people's ideas about health tend to be associated with the activities of doctors, I would agree with Hart (1985: 2) and the critics above, that health is only indirectly linked to medical treatment:

“[T]he medical profession has successfully persuaded us that our personal health depends on high standards of medical care...[yet m]edicine has not made a significant contribution to improving people's health in the past...” (Hart 1985: 1).

Lolas (1994: 3) agrees that:

“...[h]ealth is not equivalent to medicine. The restoration of the personal and societal dimensions of health care implies a recognition that healing and curing are different...that anyone can be *considered ill* without *feeling* ill and that *to have a disease* is different from both conditions” (emphasis in original).

These critiques build on McKeown's (1976) study, which showed that most of the precipitous decline in infectious diseases happened well before the introduction of effective treatment, suggesting that:

“...the threat of micro-organisms was being systematically swept away not by improvements in medical science but by other events and processes which were new to the nineteenth and twentieth centuries” (Hart 1985: 6-7).

In Western society today, the main health problems are chronic and degenerative disorders. As the list of these conditions grows longer, there is growing realisation that disease, or illness, or sickness is much, much more complex than a one way cause and effect model. Biomedicine is therefore increasingly losing its power to predict and cure disease (Gillet 1994). The knowledge that the determinants of health and disease are far broader than those premised by biomedicine, has led to the development of new explanatory models

of disease (see for example Engel 1977; Evans and Stoddart 1990; Hayes et al 1994; Townsend et al 1992; White 1981). These models conceptualise disease as not only disease, but also as sickness *and* illness. They enable us to account for a deeper and broader understanding of the disease/sickness/illness process. This is because they contextualize the process, allowing for the simultaneity and contingency of lived experiences in a way that the biomedical model does not. These new conceptualisations in turn signify a move away from modernistic ways of thinking and are designed to incorporate flexibility, dynamism, multi levelled and abstract chaos - as well as the order of our everyday lives. Many of these models incorporate biomedicine into a wider framework that also accounts for social constructions of, and meanings of illness. These are developed further in the next section.

Social constructions of illness.

The major alternative approach to biomedicine is usually known as the 'constructivist' or 'social constructionist' approach. Following Berger and Luckmann (1967) this approach introduces the idea that reality (including biomedical reality) is constructed through human actions and does not exist independently of it. In this way, it follows that biomedicine is one version of reality, not the *only* version of reality. According to Fabrega (1975):

“...biomedicine...constitutes our own culturally specific perspective about what disease is, and how medical treatment should be pursued; and like other medical systems, biomedicine is an interpretation which 'makes sense' in light of cultural traditions and assumptions about reality”, (quoted in Mishler 1981: 10).

A constructionist viewpoint argues that health and illness are therefore social and cultural facts as well as biological ones. Constructionists agree that the biomedical model strips away the social contexts of the meaning of sickness and ill health, thus abstracting the illness from the social, cultural and institutional contexts within which it occurs (Mishler 1981: 2). To a constructionist, health, illness and medical care are all social facts. They are socially constructed categories, and whether or not a particular behaviour or experience is viewed by members of a society as a sign or symptom of illness depends on cultural values, social norms and culturally shared rules of interpretation (Mishler 1981: 141). This approach to social reality locates meanings in the interpretive work of human beings. In this way, illnesses are made by people giving the label of illness to certain behaviours or symptoms. It is an active, interpretive process which is guided and regulated by social rules and norms, - central topics of inquiry in the social sciences. Following the lines of this argument suggests to me, at least, a much needed and expanded role for the social sciences in the study of things medical and relating to health.

However, social constructionism is not a flawless remedy to the problems of biomedicine and can be criticised for a number of shortcomings. The approach itself is not unified, and different thinkers have differing views on the extent to which the world is socially constructed. For example, 'radical' constructivists, such as David Armstrong (1983) deny the pre-existence of a biological base. However, most sociologists prefer to presume the existence of an external reality and argue that there are variable accounts of it. Even so, constructivist explanations fail to acknowledge the real or concrete effects of biological, social and physical mechanisms. Social constructionism denies the

possibility of progress because the lack of specific criteria to judge developments in medical science means it is impossible to evaluate the relative merits of different treatments or interventions (Nettleton 1995: 30). Related to this is the reality that medical science *has* done some good: for example the eradication of smallpox. Surely this confirms that scientific knowledge and practice are valid? Another problem, that Bury (1986) has explored in some depth, is that social constructivism runs into the insurmountable problem of relativism. If all knowledge, including medical knowledge, is relative and socially contingent, then how can the constructionist view have any validity? Bury also argues that people draw on their own resources, including knowledge and experience, in order to resist medical ideas. As such, the process of medicalisation has been exaggerated.

Although itself subject to criticism, a constructivist approach nevertheless challenges the biomedical model of disease, as defined by reference to universal, culture-free criteria. In so doing, the constructivist approach denies the biomedical assumption of generic diseases, arguing that diseases are socially and culturally defined. This allows for - indeed, one would expect - cultural variation in the specification of behaviours as signs of illness, as well as in taxonomies of disease. This is not to say that the same biological processes would not be observed in different cultures, but that they might be given different meanings. A constructivist approach departs from the biomedical model in proposing alternative definitions of health and illness. Most often, this approach has taken the form of 'social labelling' or 'social reaction' theory, where illness is defined as a type of social deviance (see for example Goffman 1963; Parsons 1951). If we define health and illness as social rather than

biological categories, it does not mean that biological processes are irrelevant or trivial, but that they need to be located within a social context, because it is *people* that get sick. The biomedical sciences alone cannot provide a full understanding of illness or adequate principles and criteria for treatment (Mishler 1981: 3). Social constructionist approaches, although subject to many criticisms, at least question the foundations and credibility of medical science, and in so doing raise the relative status of other forms of knowledge (Nettleton 1995: 33). Thus personal experiences and knowledge of illness and health may gain wider legitimacy. As Gillett points out:

“...human disease falls on a spectrum. At one end are conditions which have a clearly identifiable genetic or other pathology at their base, and, at the other, there are holistic patterns of abnormal function which cannot be broken down into easily treatable components. At each end of the spectrum a different approach is required but a common element is a need for a proper and active restoration of balanced function...” (1994: 1129).

A fuller and more adequate approach to the study of ill-health must therefore include an alternative (constructionist) perspective, where the focus of enquiry is the social meaning of illness, as well as the biomedical perspective. Doing so could make a difference to the way we think about, respond to and research issues of sickness and health.

1.3. MEDICAL GEOGRAPHY AS A FRAMEWORK FOR UNDERSTANDING HEALTH.

According to Curtis (1994: 374) medical geography is ‘the application of geographical perspectives and methods to the study of health, disease and health care’. As with other geographic traditions, this entails many different views and

standpoints, as well as differing research priorities and methodologies within the sub-discipline. The tendency is for medical geography to be wide-ranging and eclectic, with assorted claims, commitments and consequences. Because of its close connections to other disciplines concerned with health related problems, medical geography is also an integrative, multi-stranded discipline (Meade et al 1988: 3). This reflects the diverse and complex nature of health problems, and highlights the need to examine them from a multidisciplinary perspective.

Medical geography is often claimed as one of the oldest sub-disciplines in human geography and is made up of numerous approaches (Barrett 1981; Curtis and Taket 1996; Mayer 1982; Paul 1985). Any scheme that attempts to classify these approaches will inevitably be partial, but it is useful to have an appreciation of the influences shaping medical geography. Broadly speaking, there are two major research traditions within medical geography although they are not necessarily mutually exclusive (Curtis and Taket 1996; Jones and Moon 1987; Mayer 1982, 1992; Paul 1985). The two central approaches are disease ecology, and the geography of health service provision and medical care. Disease ecology is the older of the two central traditions, and focuses on the causes and spread of disease (Learmonth 1975; May 1950, 1958). This tradition of enquiry may be traced back to the work of Hippocrates, and is apparent in much medical research in the eighteenth and nineteenth centuries (Barrett 1981; Mayer 1982: 216). Disease ecology is closely allied with epidemiology and other medically based disciplines, which means it is based on biomedical knowledge and assumptions, with all the ensuing benefits and drawbacks this involves. Disease ecology analyses the interrelationships between living organisms and the physical and biological environments within which they interact, as well as

the role of human cultural behaviour in the success of the disease system. By the 1950s this approach had become heavily influenced by the dominant geographic paradigm of its day, that is, regionalism, whereby geographers tried to elucidate social and environmental causes of ill-health in a holistic manner in a specific area (Learmonth 1975; May 1950, 1958).

The second major strand of medical geography, the geography of health care planning, became popular in the mid-60s. This type of medical geography researches the provision and consumption of health care. Distribution and accessibility are its hall marks and it is closely allied with economics and sociology. Heavily influenced by location theory, central place theory and positivism, health care planning approaches look to understand health service provision and health seeking behaviour. Most studies within this category revolve around normative issues, in an attempt to optimise access, equity or efficiency (Joseph and Phillips 1984; Shannon and Dever 1974; Smith 1979; Taket et al 1986).

Jones and Moon (1987) recognise that within these two major traditions of medical geography, there are five main research strategies employed. They are cartographic, modelling, behavioural, welfare and structuralist approaches (p. 2). It is important to remember that these approaches overlap a great deal; many studies cannot be neatly assigned to these divisions, and some could be put into more than one. The first of these, the cartographic approach, maps spatial data (Cliff et al 1981, 1988; Gatrell et al 1996). Applications of the cartographic approach are used in both disease ecology and health care geography (Curtis 1990; Learmonth 1988; Meade et al 1988). One of the earliest applications in

this field were the maps constructed by Dr. John Snow during the London cholera epidemic of 1854. From them, he established the source of infected water, and put an effective stop to the epidemic by removing the handle from the offending water pump. Cartographic techniques have become more sophisticated since World War 2, perhaps most noticeably with the recent development of GIS. Medical geographers have been quick to pick up the potential of GIS, and are heavily involved in mapping the spread of mortality (Brewer et al 1997; Gardner et al 1983; Howe 1983; Wing et al 1990), morbidity (Mohan et al 1990; Nakamura et al 1997), and infectious diseases, such as HIV/AIDS (Lam and Liu 1996, 1996a; Loytonen 1991; Smallman-Raynor et al 1990).

The second research strategy can be referred to as modelling. Modelling focuses on quantifying relationships between variables (Cliff et al 1988; Curtis 1990; Hunter and Shannon 1985; Joseph and Phillips 1984; Taket 1995; Wilson 1993). Associative analyses can also be undertaken, where disease maps may identify certain causal links that are then strengthened by concurrent statistical or associative analyses. This is done using bivariate or multivariate methods (Duncan et al 1993; Jones and Clegg 1991; Jones and Duncan 1995; Shouls et al 1994; Von Korff 1992).

The third strategy, the behavioural approach, attempts to understand individual decision making. Like many other analyses in behavioural geography, it is quantitative in nature. It is presumed that by understanding individual beliefs and motivations, an aggregate picture of a situation can be drawn up. Behavioural approaches in medical geography are prone to the same sorts of criticism of behavioural geography in general, namely that models give only

weak predictive powers, also they tend to be based on neo-classical models incorporating economic rationality and perfect information (for a fuller critique of this position, see for example Johnston 1986, 1991: Ch. 5).

The fourth analytical approach in medical geography is often referred to as the welfare approach. This method asks the difficult questions of who gets what and where, and how can improvement in the quality of life be achieved by the gradual reform of existing society (Jones and Moon 1987: 2; Smith 1977, 1979). Welfare approaches are concerned primarily with notions of equity and distribution, and with the quality of life.

Lastly, the structuralist approach considers phenomena in relation to the totality of society, scrutinising the societal constraints that people face in their efforts to maintain a satisfactory level of health (Doyal 1979). The emphasis is on the links between social phenomena in our society, and a Marxist version of this approach would argue that genuine improvements can only come about by a revolutionary change to a new form of society (Navarro 1978, 1986, 1990).

Since the 1960s, other developments include diffusion models, the geography of nutrition, ethnomedicine and medical pluralism. Diffusion models of disease are based on formal geographic diffusion theory, using some epidemiological methods (Cliff et al 1981; Pyle 1969, 1980). This approach may be useful in that one can simultaneously view time and space in relation to the disease being studied. One can see the obvious links this approach has with the HIV/AIDS GIS mapping projects mentioned above. Ethnomedicine and studies of medical pluralism (unfortunately in my view) remain peripheral to research

traditions in medical geography. However, perhaps contemporary society's increasing interest in 'alternative' forms of treatment (for example, homeopathy) will stimulate an interest in these neglected areas.

Medical geography has undoubtedly contributed to the discipline as a whole as well as to our understanding of health issues. But on the whole it can be criticised for having (i) a static and unimaginative conception of space; (ii) for being over-reliant on biomedicine; and (iii) for avoiding (perhaps even ignoring) trends and innovations in contemporary human geography, particularly, the 'socio-cultural' turn. I now want to look at these criticisms in a little more detail.

In the last fifteen years, human geography has undergone massive changes in the way in which space is conceptualised and used. Investigations focus on how social life unfolds through space, and how space itself is constitutive of social processes (see for example, Gregory 1991, 1994a; Gregory and Urry 1985; Jackson 1989, 1993b; Lefebvre 1991; Pain 1997; Philo 1991, 1992; Pile and Thrift 1995; Pred 1984; Shapin 1998; Shurmer Smith and Hannam 1994; Thrift 1983, 1996). Space is a place with a meaning for everyday life (Jones and Moon 1993: 519), as well as a mediator and container of social processes. Generally speaking, however, medical geography has been slow to assess the relevance and potential of this reconceptualisation, or even make use of it (Curtis and Taket 1996; Mayer 1992; Mohan 1989). The subdiscipline tends to conceive space in a way that is Euclidian, geometric and two dimensional. Its approaches to space therefore remain essentially conservative and traditional. This criticism is, however, being tackled, and there have been a number of calls

for a refocusing of medical geography to reflect the spatiality (see Gregory 1994a) of lived experience (Gesler 1991, 1992; Hayes 1994: 129; Jones and Moon 1987; Kearns 1991, 1993; Kearns and Joseph 1993; Moon 1990: 169). In Eyle's (1993) assessment, medical geographers are now beginning to change their views of space as a container (as in spatial analysis studies), or as an attribute (in the ecological approach), and move towards a relational view in which space is implicated in human activity and vice versa. For example, Kearns and Joseph (1993), Kearns (1991) and Moon (1990) have used a structuration approach, whereas Eyles et al, quoted in Jones and Moon 1993: 519) have used a symbolic interactionist perspective. Gesler (1991, 1992) on the other hand uses humanist and structuralist approaches in a 'cultural materialism' (Jackson 1989) through which therapeutic landscapes are constructed.

A second criticism of medical geography is that it conventionally relies heavily on the premises of biomedicine. Within the medical geography literature there is growing concern to the limits of these notions (Curtis and Taket 1996; Jones and Moon 1987; Ch. 9; Kearns and Joseph 1993), as it becomes apparent that biomedicine as an explanatory mechanism for an understanding of the disease process is becoming more limited⁶. In the 1950s, when an uncritical disease ecology was the main tradition in medical geography, the assumptions of biomedicine were relatively unproblematic, because the conditions that disease ecology sought to understand were primarily acute and infectious. Since then,

⁶Geography's move away from the biomedical model as the principal view of disease is reflected in the changing nomenclature of research study groups. In recent years, both the Canadian Association of Geographers and the Institute of British Geographers Medical Geography Study Groups have substituted their 'Medical' label for that of 'Health and Health Care'.

the advent of chronic diseases with their often complex and multifactoral aetiology has considerably lessened the power of biomedicine to account for illness. One of the major problems of biomedicine is that if it is used uncritically, society becomes eliminated as a facet in the aetiology of disease and ill-health. The biomedical approach leaves little or no room to consider relations of power, or social constructions of disease, sickness or illness, for example, as constituents of the nature of social relations. A more critical approach would contextualise our understandings of health and ill-health by examining not only biomedical considerations, but also constructivist approaches and individual, societal and structural influences (such as gender and ethnicity effects) in the process of becoming sick (Davey Smith et al, 1990, 1993; Townsend 1990a, 1990b; Townsend and Davidson 1982; Townsend, Phillimore and Beattie 1988).

The cultural turn in human geography has had a huge impact on the way we currently see and learn about the world. Yet with few exceptions (see for example M. Brown 1995; T Brown 1995; Craddock 1995; Curtis and Tackett 1996; Gesler 1992; Philo 1989), medical geography, has not had much to say about it. However, this perspective is crucial, because it both confirms and examines the importance of space and place to individuals and their health (Curtis and Tackett 1996; Kearns and Joseph 1993). In some ways, this signals a return to one of the oldest traditions in medical geography (and here I am thinking of disease ecology,) but with some important and critical differences. For example, based on the work of Foucault (1970, 1976, 1977), some studies focus on landscapes of social control and their effects, bringing to light the relations of power and knowledge which impact on individuals in societies (Bell

1993; Philo 1989); other studies concentrate on the connections between structure and agency, for example (Kearns and Joseph 1993).

There are a wide range of opinions and voices caught up in the debate of what medical geography is and what it ought to be. Part of this predicament lies in differing interests and conventions within medical geography. Calls to introduce new ways of thinking into the discipline (Dorn and Laws 1994; Hayes 1992, 1994; Kearns 1993; Kearns and Joseph 1993) are sometimes resisted (Barrett 1986; Mayer and Meade 1994; Paul 1994) and at other times ignored (Wilson 1993). But it is these kinds of considerations (not forgetting the power relations embedded in them) that are important, because these are the debates that will shape the medical geography of the future. As I see it, the challenge for medical geography is to address these criticisms and move beyond its current position. I am not suggesting we abandon past research in medical geography, but I am suggesting we build on previous studies by broadening out our research questions. We need to expand our (medical) geographical imaginations by taking new theories and perspectives seriously (Poland 1992) and we need a sensitive, pluralistic development of existing research strategies (Eyles 1993; Gesler 1992; Mayer 1992; Scarpaci 1993). This could achieve a greater sensitivity towards our research subjects, as well as an awareness of the complexities of health issues. We then will be able to speak about multiple *geographies* of health, illness and health care, not solely *a* medical geography.

If we know that health does not equal health care (Hayes 1994; McKeown 1976, 1988; Dubos 1959) and if we know that sickness is multifactorial in origin (Evans and Stoddart 1990; White 1981), we must look to

wider issues that may be concerned with health. Considering questions that are outside the traditional bounds of biomedicine and medical geography would enhance our understandings of the contextuality and contingency of social life as it relates to health. This is the only way that we will be able to broaden and deepen our understandings of health as well as plan future strategies. The need is therefore to consider other theoretical and practical issues that may also be simultaneously impacting on health. This invites an expanded role for theory development, which, according to some commentators, remains one of the greatest challenges for contemporary medical geography (Curtis and Taket 1996; Jones and Moon 1987 Ch. 9; Kearns and Joseph 1993). This challenge has stirred up considerable discussion, which continues to the present (Dorn and Laws 1994; Kearns 1994; Litva and Eyles 1995; Mayer and Meade 1994; Paul 1994; Philo 1996). Yet generally, medical geography overlooks socio-theoretical developments within human geography and often abstains from current debates such as postmodernism or feminism for example. This is problematic because without broadening its theoretical base, medical geography will continue to be (among other things) gender- and colour-blind (Dyck 1992; Dyck and Kearns 1994; Mathews 1993: 91; Mohan 1989) and remain largely ignorant of other minority groups, such as disabled people or gays and lesbians (although cf. M. Brown 1995; Butler 1994; Dorn and Laws 1994; Parr 1998).

1:4. CONCLUSION.

In this chapter I have outlined competing conceptions of health and the main premises and career trajectory of medical geography. I have done this in order to expose the strengths and weaknesses of these approaches. Generally,

medical geographers have adhered to an uncritical acceptance of Euclidian space and biomedicine, producing work that lacks both passion and compassion. There has also been a marked reluctance to engage with some of the current theoretical debates within human geography, and a general disregard for gender and colour (also (dis)ability and sexuality) issues. The sub-discipline therefore remains essentially conservative and uncritical. There are, of course, exceptions to these criticisms (T. Brown 1995; Dorn and Laws 1994; Dyck 1995; Gesler 1991, 1992; Hayes 1992; Kearns 1993, 1994; Parr and Philo 1995; Philo 1989; Scarpaci 1993) although they are relatively few and far between.

These exceptions form a 'third wave' of medical geography. A common feature of this genre is that they draw widely on literatures that up until now have been overlooked by medical geographers. These literatures stem largely from critical social theory, not necessarily in the sense of the Frankfurt School, (or in the Habermasian sense,) but in that they challenge the current social order and/or give us new insights into new and old problems. These literatures therefore strive to make sense of our social world and effect change. Key aspects of these social and cultural theorisations are becoming increasingly important in medical geography.

For example, Dyck (1995) calls for a recasting of medical geography, in a direction that focuses on the relationships between place and health experience (p. 307). She describes the complex interweaving of space, physical impairment and gender in the lives of women with multiple sclerosis, and documents how this interweaving affects their experience of place. The experience of place is also a prominent theme in the work of Kearns (1991, 1993, 1994, 1996a). He

considers health in terms of both the experience of place *and* issues of locational relationships. He suggests that a reformed medical geography needs to be resituated within social geography because of interest in health/place relationships in policy and research. This suggestion is rejected by some medical geographers (Mayer and Meade 1994) and welcomed by others (Dorn and Laws 1994). In addition, Kearns bemoans the relative paucity and marginalised place of rural health research in medical geography (1994: 106). Much of his work has centred on the Hokianga in New Zealand, an area with a population of roughly 9000, over half Maori. He has shown how notions of place are important for small and isolated communities, and how medical settings such as clinics function as arenas of social interaction as much as arenas of medical treatment.

Gesler explores the links between cultural geography and medical geography (1991, 1992). Focusing on 'therapeutic landscapes', his ideas '...incorporate traditional human-environment interactions in landscape formation, and several themes from structuralist and humanist perspectives, [as well as] some guiding principles of holistic health' (1991, quoted in Philo 1996: 38). Philo (1996) suggests that the interweaving of power, knowledge, action and (occasional) resistance comprises a vital step forward for medical geographers (p. 37). His own work examines this nexus closely, within the context of what he terms 'the mad business' (1996: 35). His analysis is concerned with how space was organised within nineteenth century lunatic asylums, as well as how place, and particular locational attributes affected the siting of asylums (1989). Philo's concerns focus on mental health, but they are equally applicable to physical illnesses too.

Language and discourse are intimately related to power and knowledge, but as yet, little work in medical geography looks explicitly at their role⁷. T. Brown (1995) argues that the discourse of AIDS and HIV is entwined with broader reconstructions of health and disease. He suggests that (re)defining of the boundaries of health can be made apparent through an evaluation of AIDS discourse. He therefore examines temporal and spatial locations of HIV/AIDS within the confines of language in order to show how its spatialisation has been

⁷Deriving from the work of Saussure, poststructuralists assume that meaning is produced *within* language, not reflected *by* it. Writers such as Derrida, Foucault and Kristeva assert that words mean what they do through their arbitrary relations *with* each other, rather than through their relationship to an extra-linguistic reality. Thus a cat is a cat because it is not a bat or a cap. Identity becomes defined through difference (Shurmer Smith and Hannan 1993: Ch. 8). This is an important point, and is further considered in Chapter 2. Language is therefore constitutive of, rather than reflective of social reality (Pratt 1994: 468). As a result, any fixed meaning or correspondence between language and the world, or any fixed reality, truth, or fact to be the object of enquiry, is denied (Blackburn 1994: 295). Post-structuralism thus promotes the notion that 'reality' is a thoroughly discursive phenomenon, a product of the various codes, conventions, language games or signifying systems which provide the only means of interpreting experience from a given socio-cultural perspective (Sarup 1993: 168). Meaning is not fixed, but constantly shifts. It can therefore be the focus of fierce political struggle (Peet and Thrift Vol 2 1989: 23). Looking for the shifting, sideways movement of language, and its web-like complexities, highlights sites of dispersal, fragmentation and contradictions within language (and by extension, the text). This is where the subversive act of deconstruction can challenge initial readings and interpretations of the text. From this perspective, language becomes a medium for defining and contesting social action, and reading and writing can become (political, for example) interventions. This underscores another characteristic of poststructuralism: a concern over the nature of writing (and therefore) textual materials (Giddens 1987: 195). Writing styles should be taken seriously because the way you write is constitutive of what you write. For a poststructuralist, changes in style will lead to changes in content. Therefore style is not trivial in getting the message across - it is crucial to what you're getting across.

used as a metaphor for the shifting role of health policy in UK government policy. His aim is not to discover some ultimate truth, but to discover how the multiplicity of languages influence the construction of boundaries, and (re)formulate ideas of health. Notions of deviance, and the language of exclusion, he argues, are salient characteristics of AIDS discourse. He concludes that by investing the body with notions of individual responsibility and practices for good health, biomedical discourse has been replaced by a discourse constructed around ideas of health promotion and disease prevention. Through the reorganisation of health care, the individual responsibility of the patient and a new language of health have become apparent. This new language is a professional language of health, where ‘the cause is individual and cure is prevention’ (p. 6).

Finally, Dorn and Laws⁸ (1994) suggest what a loosely poststructural framework for medical geography might look like. They argue that the

“...recent debates about the body, the identities attached to it, and the ensuing “politics of difference”...are of fundamental importance to the concerns of a rewritten medical geography...[p]oststructuralists and radical feminists challenge us to interrogate the *embodied* subject positions which are being forged in contemporary society,” (p. 106, emphasis in original).

Furthermore, they argue that

⁸I would like to acknowledge the encouragement Glenda Laws gave me at the start of this project, and it was with great sadness that I learned of her untimely and tragic death whilst I was in New Zealand. In my opinion, she would have become one of the most influential people writing in the field of ‘medical geography’ today.

“...by continuing to ignore the social construction of the body and the struggles of new social movements, medical geographers will fail to take advantage of the lessons of social theory.” (p. 107).

These ‘third wave’ ideas are precisely the issues that I am interested in: the interweaving of place and physical impairment; the experience of place and health; the marginalised place of rural health research; the intersections of power, knowledge, action and resistance; language and discourse; the body; identity; and the politics of difference. In examining certain elements of identity, I aim to show how ‘race’/ethnicity, health and place are inextricably linked. I am interested in how personal and group identities become ‘othered’ and ‘spoiled’, through being marginalised by sickness, ethnicity and rurality. In addition, I am interested in marginalised conceptions of the body, and what this means for the way health issues are approached in specific areas. Taking the advice of Dorn and Laws and others, I must therefore turn away from the ‘traditional’ canons of medical geography literature, and draw on wider social and cultural theories. This I do in Chapter 2, where I map out more fully the theoretical ideas that have inspired my thesis. These ideas fall under three broad headings: discourse, otherness and the body.

Although I have criticised medical geography for particular faults, they are not irresolvable and there is certainly a growing body of literature (this thesis included) that attempts to address them. This study thus aims to build on the critiques of biomedicine and its corollary, medical geography, by focusing on the social side of illness as much as the ‘medical’ side. To accomplish this I shall be drawing from specific theoretical literatures so that the study might contribute towards the development of a more nuanced and critical medical geography, one

that takes account of the contemporary debates surrounding the intersections between health and social life.

CHAPTER TWO: THEORETICAL IDEAS AS INTERPRETIVE TOOLS.

2.1. INTRODUCTION.

In a recent editorial, Graham Moon declared the need to bring together theory and applied work in health-related research (1997: iv). The problem, as he sees it, is that whilst it is easy for geographers doing health research to claim their work is applicable, it is often under-theorised, and this means that applied research may contribute little to academic advancement. He also argues that often, where theory is used, it is outmoded. In a similar fashion, I criticised 'traditional' geographies of health and health care in Chapter 1; I also considered recent efforts to invigorate medical geography, both from theoretical and practical standpoints. In this chapter, I want to build on those 'new' health geographies as well as to introduce other strands of social theory that are useful for this thesis, so that practical health research and theoretical insights might work together for a purpose, that is, theorised action research. From the standpoint of medical geography, contemporary social theories might be helpful in terms of making sense of the links between health and marginalisation in terms of colour, gender, or rurality for example. Relatively little consideration has been given to women, people of colour and immigrant communities and it is possible that theories of feminism or postcolonialism, for instance may be useful for shedding light on some of the health issues faced by these minority groups. Why have the health problems of certain groups been neglected? Why is it that marginalised groups often have a poorer health status than non-marginalised groups? How and where do power relations within society fit in? Why do

geographies and histories of various groups matter? In borrowing from social theory and using it as a vehicle for analysis and interpretation, I am trying to work through a critical medical geography that engages with some of the theory and methods of contemporary social science. The aim is to highlight new ways in which medical geographers might think about health matters.

I see theoretical issues as providing a focus for analysis and further investigation, not as ready-made methods for solving research problems. This highlights the importance of drawing on theories, not imposing them (Reinharz 1992: 72). Moreover, as Best and Kellner (1991: 266) argue, because there is no one absolutely valid and correct perspective in which to ground it, social theory must be open to different approaches and standpoints (see also Elliott 1994: 166-169). A broad knowledge of comparative literatures opens up a greater appreciation of problems and possibilities in terms of research questions and strategies, and as theoretical approaches are necessarily intertwined with social and political processes, assessing competing or complementary theories demands sensitivity to local, social and ethical issues, as well as technical ones. These points have guided my selective use of current literatures and debates. Diverse theoretical positions could bring together any number of viewpoints, but the particular literatures I am drawing on are broadly situated within the fields of postmodernism/poststructuralism and postcolonialism¹. These bodies of

¹These social theories are closely affiliated. For example, poststructuralism is often considered a sub-set of postmodernism so that ideas of discourse for instance, feature in both. There are also close links and overlaps between postmodernism and postcolonialism (consideration of the other in terms of skin colour and giving voice to marginalised groups for example). Whilst I might be accused of 'rushing to the post' (Soja 1989: 5), I agree with Soja that "...too many opportunities are missed by dismissing postmodernism [and by extension

literature encompass many diverse strands of thought and are increasing at what seems like an exponential rate. I am therefore drawing on three very specific theoretical strands, in order to develop a series of arguments which will inform my thesis, and in an attempt to produce work that is effectively theorised action research. These literatures concern (i) the theoretical and practical natures of discourse; (ii) otherness; and (iii) the body. This chapter examines these theoretical orientations in detail.

Why focus on these ideas? It seemed to me they would be the most useful in helping me make sense of what people said about their health experiences. In brief, I had gathered different stories about similar (health) realities and I wanted to think through why they differed. The stories were mainly about infirmity and the challenges that managing the activities of daily living presented in a socially and economically marginalised environment. They show that there are fundamental differences in the discourses of life experiences, including those of health, and that these discourses are intimately linked with the discourses of group identity, social marginalisation and embodiment. As outlined in Chapter 1, these issues are the focus of my research. They include the interweaving of place and physical impairment; the experience of place and health; the marginalised place of rural health research; the intersections of power, knowledge, action and resistance; language and discourse; the body; identity; and the politics of difference. To uncover why and how certain group identities become spoiled (that is, othered in some way), means exploring

poststructuralism and postcolonialism] as irretrievably reactionary” (ibid.). In my opinion, it is at least worth investigating their potential usefulness, particularly in the light of Moon’s comments above.

discursive practices as they relate to the construction of groups perceived as somehow 'different'. Thus literatures of discourse, otherness and the body seemed a reasonable place to start. Interpreting discourses of health could be one way of reaching an understanding of place-based experiences of health and ill-health.

By drawing on social theories, I am aiming to analyse the constructions and interpretations of health discourses amongst Maori and Pakeha in the Hokianga region of New Zealand, but for very practical reasons. This thesis sets out to examine whether and to what extent, discourses and practices might be implicated in the geographies of exclusion, particularly in terms of health and 'race'/ethnicity. Some of the questions I shall consider are as follows: are there any discursive health differences between different ethnic groups? Is there a dominant discursive attitude towards health and illness? Does it differ from other constructions of health? Do these discourses serve the mechanisms by which others may become excluded from the mainstream? What are the mechanisms by which such discourses serve to exclude others in the mainstream? Are the current changes in the New Zealand health system detrimental to certain marginalised populations? If so, why? Are these discourses matched by practices? How are other health systems treated in hegemonic society?

2.2. DISCOURSE.

The word 'discourse' has been used as an umbrella term that refers to all forms of verbal communication in a society (Finnegan 1992: 14), and 'a

continuous stretch of language containing more than one sentence: conversations, narratives, arguments, speeches' (Blackburn 1994: 107). More recently, however, influenced by currents in postmodernism and poststructuralism, 'discourse' has taken on more subtle meanings in both theory and practice. Discourses are now also implicated in the ways in which meaning becomes established. In this sense, they can be understood as practices that systematically form the objects of which they speak (Fisher 1992; Sarup 1993: 64; Smart 1985). A Foucauldian approach to this would search out how and why we have come to know what we know; that is, what has made the conditions of such knowledge possible? Discourse therefore operates at various levels - via the unconscious, through words, speech and conversation, right up to defining and perpetuating what have often become socially accepted 'common-sensical' ideas and societal norms (Angus and Langsdorf 1993; Smart 1985).

All areas of the social sciences have shown an increased interest in discourse when trying to understand the role of language in maintaining social order and notions of reality (Curt 1994: 116; Lupton 1994: 17). Language is socially created and does not exist in a vacuum: discourses are therefore contextual, embedded as they are in historical, social, cultural and political settings, and are used in certain ways for certain purposes (Lupton 1994: 17-18). In addition, they are textual and intertextual, drawing upon other discourses to achieve their meaning. The meanings in discourse however, are not singular or fixed; terms take on specific and contextually grounded meanings through the discourse as it is shaped and developed by speakers. Discourses and texts do not have a fixed status in their own right, nor are they explicable in terms of the originality of the author. They can only be understood in the context of other

related texts through which the readers/audience make sense of it. In this way, therefore, discourses are thoroughly textual, contextual and intertextual (Finnegan 1992; Mishler 1986: 64).

Gregory (1994: 136) describes discourse as 'the ensemble of social practices through which the world is made meaningful and intelligible to oneself and to others'. He uses the above ideas to emphasise three interconnected features of discourse. These are its embeddedness; its naturalising function; and its situated character (1994: 136). Discourses are not free-floating, autonomous creations, but intricately and fundamentally involved in the conduct of everyday life. Their embeddedness means they have marked effects, for example, Gregory cites the complicity of the discourse of human geography in the history of colonialism (*ibid.*; see also Carter 1987; Crush 1994; Livingstone 1994; Mitchell 1988; Said 1978). In a similar fashion, the embeddedness of medical discourse has done much to shape public perceptions of certain conditions, for example, AIDS. Secondly, the naturalising function of discourse helps frame the character of the taken-for-granted world in such a way that particular views of the world and subject positions within it become unquestioned and seen as 'common-sensical'. To extend Gregory's example, this naturalising effect meant that in nineteenth and early twentieth century England, ideas of white supremacy were largely unquestioned and perceived as common-sensical. Likewise, in the contemporary health arena, the discourses of biomedicine are rarely problematised, and for many, both lay and professional, biomedicine remains the only legitimate method for dealing with health issues. Thirdly, the situated character of discourse can only ever provide partial knowledges which are determined by particular constellations of power and knowledge and are

therefore always open to contestation and negotiation. Thus the situated and powerful nature of nineteenth century English colonial discourse meant that the English viewpoint was the only legitimate viewpoint; that protesters and sufferers voices frequently went ignored and/or unheard. And biomedicine itself is a situated knowledge, determined by certain clusterings of power and knowledge, located largely in late twentieth century capitalism and perpetuated by key players with vested interests, such as politicians and medical professionals.

Clearly, discourses are implicated in relations of power. The connections between them, social processes and power are opaque, but a critical awareness of language and discourse can help yield this opacity more transparent (Gregory 1994: 468; Lupton 1995: 13). Foucault is one of the best known writers on this subject. I am particularly interested in Foucault's work because I have worked in the health field for fourteen years as a registered nurse. His critique of medicine has had direct implications for the ways in which I view my profession and carry out my work, both in clinical settings and in the academy. For Foucault, the term discourse does not refer to language or social interaction, but to relatively well-bounded areas of social knowledge, including medicine. Scrutinising the 'micro-politics' of power relations in various contexts has led Foucault to conclude that the systems of knowledge ('discourses') which organise the techniques and practices for exercising social control within particular, localised contexts are inextricably linked (Harvey 1990: 45). Foucault's discourse theory looks for what can be said and the conditions under which it becomes possible to say these things. Discourses therefore constrain and enable what we can know. For example, Foucault has shown how the flow of nineteenth century medical

discourse was able to identify the poor and insane as unhealthy. Moral and medical fears of contagion exacerbated the power of science to define their conditions and treat them accordingly. In the same way today, medical discourse has contributed to stereotyping people with HIV/AIDS as belonging to certain 'deviant' 'risk groups' such as gays or IV drug users (Crawford 1994; Glick Schiller et. al. 1994). More than anyone, Foucault has shown that 'diseases' can no longer be seen as natural events in the world, occurring outside the language with which they are described. Instead, a 'disease' is the product of medical discourses which in turn reflect the dominant mode of thinking within a society (Turner 1995: 11). The work of Foucault has fundamentally changed the way (social) scientists think about and analyse the (medical) world (see for example Fox 1993: 30; Tilley 1990; Turner 1995: 11).

Discourses change over time and space, so there are multiple discourses to examine. There are also multiple ways to examine discourse, and the label 'discourse analysis' has been applied in very different ways in the social sciences (Marshall 1994; Potter 1988; Potter and Wetherall 1994: 47; Wetherall and Potter 1988). Silverman (1993: 120-124) suggests that there are certain themes common to interpreting any discourse: (i) a concern with a broad range of activities often related to more conventional social science concerns (for example, gender relations, social control); (ii) the analysis of ordinary conversation as a baseline for understanding talk in institutional settings does not necessarily have to be used; (iii) when interpreting discourse one can work with far less precise transcripts than conversational analysis requires. 'Traditional' discourse analyses look to stretches of speech as essentially cognitive phenomena or as sets of linguistic laws, whereas studies influenced by

current social theory (and particularly Foucault) attempt to show how social institutions and practices can be understood through the workings of a set of discourses. These latter studies argue that language and communication must be examined in actual social settings, and that in order to analyse or describe discursive rules and practices, we must always turn to specific historical conditions, to 'the piecemeal, the local and the contingent', (Finnegan 1992: 43; McHoul and Grace 1993: 5). Language, talk and texts are all seen as social practices that are the products of experience and which constitute the realities in which we live. They are therefore sensitive barometers of social process and change (Lupton 1994: 18; Pease Chock and Wyman 1986: Ch. 1). Emphasis is placed on how discourses are constructed in a particular way and permit the production of specific actions. These discourses then become sustained by various social practices.

This kind of thinking has done much to further our understanding of social life, although it has been the subject of many critiques. For instance, Eagleton (1991: 41) has argued that there is a tendency to overemphasise discourse at the expense of practices (see also Thrift 1996). Hoy and McCarthy (1994: 163) have developed this critique further, suggesting that the emphasis on discourse has raised many new problems, but ones where we lack the appropriate analytic tools and therefore any obvious solutions; in other words, examining discourse has done nothing to actually solve problems. Ward (1996: 160) suggests that although studies of discourse and its effects profess to emancipate the disenfranchised and different 'subject victim groups', it actually reinforces social and cultural disempowerment and reproduces the existing social hierarchy of which academics are major beneficiaries. And Wetherall and

Potter (1989: 89) point out that although these types of studies are becoming more common in the social sciences, they do not pay attention to everyday discourse. Throughout this study, I have made a conscious effort to address these criticisms. Thus I am interested in discourses *and* practices; in improving things for a specific section of the population without reinforcing social hierarchies, and in looking at an everyday (and sometimes mundane) discourse.

Discourses are made up of texts, and by closely reading and rereading texts, several issues can be brought forth for analysis. Variations within and between texts can be used as a counterpoint to expose contradictions. Why is the text this way and not that way? Why has the speaker chosen these words rather than any others? What is said, and more importantly, what is not said? Differences within and between versions highlight the fact that discourse is a constructed, manufactured entity; there is nothing absolute or natural about its eventual form. Variations in texts may facilitate the identification of features of construction. Even minor features can potentially be used to work through questions of how the discourse is arranged and oriented to action. An assessment of the rhetorical organisation and content is also an important part of examining discourse. Instead of asking questions about how a version relates to 'reality' (itself a problematic concept, see Berger and Luckmann 1967), looking for the rhetorical organisation focuses questions on how one version relates to competing alternatives, that is how persuasive the version under scrutiny is. Thus the quality of any analysis will be dependent on how certain analytic interpretations can be justified, as well as the quality of the write-up.

Subjectivity grounds our understanding of who we are, and language is the medium for defining and contesting social organisation and subjectivity (Fetterman 1993: 1; Pratt 1994: 468-469). As language and, by extension, discourse are so significant in shaping our subjectivities, it is important that we examine them. I am particularly interested in the formation, process and results of discourses of otherness; particularly those of 'race' and 'illness', because my main interests lie in the 'race'/health nexus. Thinking through discourses of otherness in terms of health and ethnicity is a worthwhile endeavour because it could help us understand the elusive processes and tangible effects of being made other in these terms. Although I am interested in the intersections of health and ethnicity, I am aware that these categories are not automatically 'out there', but have been socially constructed. Whereas humanist versions take subjectivity as given in experience, poststructuralists take an anti-humanist stance, and 'decentre the subject'. They argue that these subject positions (the 'ill', the 'ethnic') are constructed within and through discourses (Pratt 1994: 604), and that because discourses shape forms of consciousness and unconsciousness, they have very real effects (Eagleton 1983: 210). This opposes the idea that the subject is autonomous, rational and has a stable core, but is always becoming - 'a kaleidoscope of different discursive practices' (Peet and Thrift 1989: 23), 'continually in process, as a site of disunity, conflict and contradictions, and hence political change' (Best and Kellner 1991: 266). Subjects are thus 'constituted at the intersection of different discourses' (Gregory 1994: 190), rather than being separate from them. The circulation of discourses and practices therefore shape subjects rather than subjects shaping them.

Discourses may well shape our subjectivity, but so also does experience. Thus although I think notions of discourse are important for our subjectivity, and for this study, I do not think our subjectivity is constructed solely out of discourses. This is similar to Eagleton's critique, that if reality is constructed only by our discourse rather than reflected by it, how can we ever know reality itself, rather than merely knowing our own discourse? (1983: 143-144). It also reminds us of the necessity to bring practices back in (Thrift 1996). But notions of discourse are important because they encompass many crucial ideas, for example issues of fluidity, indeterminacy, intertextuality, and reflexivity. They also raise new questions and invite us to see and think about the world in novel ways, for example, how discourses are implicated in the creation of others.

2.3. IDENTITY, DIFFERENCE AND THE FORMATION OF OTHERNESS.

Mary Douglas has argued that ritual and classification is crucial in the production of meaning and the reproduction of social relations (1966). Using the example of dirt, she has shown how rituals extend to all aspects of every day life. What we perceive as dirt is a function of our ideas about hygiene and respect for social conventions. According to Douglas, dirt is simply matter out of place, there is no such thing as absolute dirt. But it offends against order, and our efforts to remove it are attempts to organise and purify the environment. Like the distinctions between insiders and outsiders, the construction of categories such as clean and dirty, are the products of cultural systems of classification which create order (Woodward 1997). The construction of categories and the cultural systems that create order, profoundly influence the formation of identities.

Identity has been described as ‘...the interface between subjective positions and social and cultural situations’ (Woodward 1997). Questions of identity, difference and otherness have recently become central topics for investigation in the social sciences and humanities (see for example, Ashcroft et al 1995; Bird et al 1993; Chambers 1994; Keith and Pile 1993; Lash and Friedman 1992; Pile and Thrift 1995). Given the current state of world affairs, and the wars being fought over these issues, their significance is undeniable. One only has to listen to the evening news to hear regular reports on the conflict between Israeli and Palestinian, or Serb, Croat and Muslim to name but a few. Disputes such as these have sparked an interest in trying to understand identities, because this understanding can be used as a conceptual tool with which to make sense of social, cultural, economic and political changes (Woodward 1997: 1). One can see from these examples that the struggle to assert different identities has material causes and consequences. Yet identities in the contemporary world are formed through and by many other factors as well as nationality and ethnicity. They also derive from social class, community, gender and sexuality, for example - sources which often conflict in the construction of identity positions and lead to contradictory fragmented identities. However, identity gives us a place in the world, and is the link between us, and the society in which we live (Woodward 1997).

Identity shapes the ways in which we are the same as others as well as the ways in which we are different, but it is usually the differences between us that most clearly define our identity. In social relations these forms of symbolic and social differences are established in part through the operation of classificatory systems called binary oppositions and the need to create order.

Identities become framed in terms of oppositions such as urban/rural, man/woman, white/black, healthy/unhealthy, normal/deviant (Gilman 1985, 1988; Woodward 1997). These groups become seen as insiders or outsiders, as us and them. In addition, one side of the oppositions is always seen as superior to the other, largely for historical reasons. Thus in the examples given above, and in the experience of our own society, man has been perceived as superior to woman, white as superior to black, healthy as superior to unhealthy, and normal as superior to deviant. These notions of sameness and difference are marked symbolically through representational systems, and socially through the inclusion or exclusion of certain groups of people. Identity, therefore, is not the opposite of difference, but is reliant upon it.

The most common form in which constructing different identities appears is in binary oppositions. Saussurean linguistic theory maintains that binary oppositions are essential to the production of meaning (see footnote 7, Chapter 1). For example, prior to the arrival of Europeans, the indigenous inhabitants had no word that they called themselves. There was simply no need for one. The word Maori, meaning common person, only came into use with the arrival of strange and unfamiliar peoples who were very different to them. It was only through the difference of Europeans that Maori began to define themselves.

Identities are formed in relation to other, different, identities, that is in terms of the 'other'. Although identity is marked by difference, some differences are seen as more important than others, especially in particular places and at particular times. Identities are therefore historically and geographically contingent. This suggests that identities are not fixed and unchanging, but

constantly shifting, whether focusing on a day-to-day basis or over a long period of time. Identity is maintained through social and material conditions - if a group is symbolically marked as different, that will have real effects because the group will be socially excluded and materially impoverished. Powerful groups will attempt to 'purify' space at the expense of minorities, who they view as defiled and polluting. As Sibley argues, '...in the developed society of racism, sexism and the marginalisation of minority groups, exclusion has become the dominant factor in the creation of social and spatial boundaries (Sibley 1995: 18).

Sibley continues that the geographies of exclusion are literal mappings of power relations and rejection. Although the nature of difference varies through time and space, the imaginary employed in the construction of geographies of exclusion is remarkably constant (ibid.: 86). The nature of exclusionary discourse is such that it draws particularly on notions of colour, disease, sexuality and nature (?rurality), but, Sibley argues, they all come back to the idea of dirt as a signifier of imperfection and inferiority. When the dominant culture defines a group as different, the members of these groups are imprisoned in their bodies. Dominant discourse defines them in terms of bodily characteristics and constructs those bodies as ugly, dirty, defiled, impure, contaminated or sick (1995: 19).

These kinds of identity issues are important for this thesis for a number of reasons. First, I believe that any honest research project should acknowledge the researcher's own position and identity. I do this in Chapter 4. Doing this helps reveal the context of the project and the researcher's background, both of which profoundly affect the success of the project. Secondly, as I outline in

Chapter 3, New Zealand histories show a Pakeha² tendency to treat Maori as intellectually and morally inferior, in large part as a result of them being viewed as other, because of their colour. Third, that unhealthy and sick people are marginalised in our society in many ways, particularly through being socially excluded and in having an effective voice that is heard by people in positions of power. This is also the case for many rural people. Quite simply, these others have been, and still, are viewed as ‘matter out of place’.

Social constructions of the other have a long and elaborate history. Examples include the mentally ill, or those with a different skin colour to one's own. What is being othered is not the people per se, but a certain facet of their identity, that is viewed as deviant or different to a dominant societal ‘norm’. Now, identities change, so others and their otherness is not a concrete social group. What is being othered is a group's blackness or illness (or whatever). But if people identify themselves around their ‘race’/ethnicity or ill-health, for example, then those people will be ‘othered’. These others have been rendered largely invisible, obscured and separated from mainstream academic research where studies have predominantly focused on a white, middle-class, straight male world (Philo 1992a). But hidden others (which include for example, people of colour, children, gays, lesbians, women, the sick) also inhabit the world and othering is the process where a social distance is created by a hegemonic part of society, between their ‘norms’ and those who differ from it. Othering is thus shaped against another idea (a binary opposition): that is, to have an other you need something against which to compare it (often Self). Moreover, conceptions

²New Zealander of European origins or extraction.

of the other poses an inherent hierarchical relationship, where what is constructed as 'normal' is considered superior to the 'abnormal'. The result is that being constructed as the other is often pejorative and disempowering (Duncan 1993a: 43). Others are perceived as out of control and social distance is invented in order to maintain a semblance of control. A society's loss of control gets projected onto the other; in this way they become 'deviant' and socially distanced, that is marginalised, from the 'norm'. The notions of projection of disorder and social distance are thus crucial in the formation of others.

The notion of 'us' and 'them', of the other and self, has fundamental geographic and spatial aspects to it. The spatiality of everyday life impacts widely upon us, especially in the 'ways constellations of power-knowledge are inscribed through space and through which particular subject-positions are constituted' (Gregory, 1994: 584). These constellations of power/knowledge in terms of 'race' for example, can be seen through the histories and outcomes of colonialism, the (enforced) movements of peoples across the world, and the treatment and condition of those involved. In terms of disease or ill-health, medical discourse's specific constellations of power/knowledge (at present, biomedicine) have defined what constitutes normal and abnormal categories for the body, as well as what constitutes a disease. It is the *collisions* of specific power-knowledge constellations, in this case, of 'race'/ethnicity and of biomedicine and 'disease', that are the focus of this thesis.

I believe it is important for geographers to talk about otherness and marginalisation for two reasons. Firstly, because the effects of being 'othered' involve some kind of social and therefore spatial exclusion: this has always been

a key issue on the research agenda of social geography. Secondly, because the material consequences of social distancing and marginalisation, however constructed, are very real, and therefore merit critical and detailed examination. In this project, forms of otherness are important because disease, 'race', illness and 'rurality' are prime examples. Regardless of why or how a person or a group of people are perceived to be different, there can be potentially devastating prejudicial consequences. At a material level, people construed as other may live their lives under constant stress, facing discrimination and barriers at every turn both in a macro (structural) and micro (individual) context. There may also be other tensions: verbal and physical threats or violence, and perhaps at the most extreme level, literally living in fear for their own lives. Failure to take these issues seriously, runs the risk of ignoring others entirely and this only negates the questions and problems of otherness further.

The construction of others is a complex process and there are many different forms. Moreover, these constructions have social and spatial consequences. Exploring the geographies of 'otherness' in terms of social and cultural marginalisation and exclusion may help to demystify the process of othering and challenge certain common-sense assumptions about people who are perceived as an other, for whatever reason (Barker et al. 1985; Carter 1994; Sibley 1992, 1995). Why have/are others often been seen as the proper and inevitable subjects of social science? All too often it is forgotten that many (social and by extension medical) constructions, while necessary for, say, expediency, (classification for whatever purpose,) are not real in the sense that they are given or essential. Objective and empirical social science repeatedly fails to question the nature and origins of these categories, forgetting to

acknowledge their social invention. This type of science is a product of the Enlightenment, a project that is increasingly coming under cross-examination. Questioning this style of science has opened up new ways of thinking which have suggested alternative ways of conceptualising others. This often starts with an explicit recognition that social classifications are constructs only, even these constructs may have very real effects. Recognising the existence of these social constructs may be the first step in changing common-sense assumptions held by society-at-large about certain groups of people.

In this project, rather than taking others as empirical objects for my own academic gaze, I have tried to do research in a way that renders others less of a topic for investigation, and more of a way of examining my own cultural constructions and the consequences they might have. This involved a co-operative project that was beneficial both to others and to me, whilst at the same time recognising that constructions of otherness are invariably, and everywhere, social. In this way, I hope it is possible to acknowledge my own place in the constructions of these categories. I want to do this on the assumption that this could be prime site from which to start dissolving some of the misconceptions of others in our own times. Furthermore, following Spivak (in Shurmer Smith and Hannam 1994: 129) I would argue that although we might not be able to speak *for* people, we can speak from our *own* vantage point; and I think that this is where social science is of such crucial importance. Acknowledging and analysing constructions of the other is thus a step in breaking down the essentialising categories of 'Us' and 'Them', for example, Maori and Pakeha, or diseased and healthy. I believe that contextualised

historical and geographical studies could do much to enhance our understanding of other lives.

Constructing others is a common occurrence in both lay and academic logic, but in so doing, there is a tendency to assume that all others are or eventually become essentially the same - a tendency to lump others together by virtue of specific characteristics. I would caution against this. Imagining others who share a similar feature (be it gender, sexuality or whatever) denies the reality that there will probably be more differences than similarities. There may be considerable benefits in trying to unravel the ways and consequences in which multiple otherness collide in and through the bodies of real people. The coming together, in the spaces of one body, many different types of otherness raises questions of hybridity, and in a sense this hints at Homi Bhabha's notion of a Third Space - where social hybridity potentially fashions a new place from which to speak and act (Bhabha 1994, 1995; McLaren 1992: 134). Bhabha argues that this Third Space is the precondition for the articulation of (cultural) difference and it is in that space that we can speak of others and ourselves. Third Spaces, then, may be a crucial starting point from which to initiate articulating the problems and knowledges of otherness and difference.

Otherness and 'rurality'.

Rurality is a feature that has become closely associated with (embedded in) ideas of nature, and nature, as Sibley notes, '...has a long historical association with the other' (1995: 26). I see the otherness of rurality as having two overlapping dimensions. First, the idea of rural itself as an other: slow,

unchanging and conservative, as opposed to the idea of urban - fast-moving, exciting and cosmopolitan. The rural was always an 'other' in modernity (Crouch 1997: 191). Second, that there are people living in rural areas that don't conform to rural stereotypes, are out of place if you like, and are therefore construed as 'rural others', for example, gypsies or New Age travellers (Sibley 1995). This oversimplifies reality considerably, but suggests that the otherness of rurality operates on different scales - at a rural-urban scale (or continuum), as well as within rural areas themselves. The recent debate between Philo (1992a, 1993) and Murdoch and Pratt (1993, 1994) alerts us to these multiplicities of otherness that exist in the countryside, and the need to be sensitive to difference (see also Cloke and Little 1997; Milbourne 1997). A central feature of this debate concerns difference, marginalization, identity and power within the rural arena (Milbourne 1997: 5). It revolves around the extent to which '...understandings, evaluations and uses of understandings about the discursive power within socio-cultural constructions of the rural can be channelled collectively into an agenda for change (Cloke and Little 1997: 4). This debate also questions whether 'giving voice' to people is enough to address issues of power in rural areas. I accept that often, 'giving voice' to rural others will not be enough to change configurations of power in the countryside. However, I also believe that in the case of this project it could be. I believe the voices will be listened to, and will effect change. In differing combinations, the otherness of rurality, and rural others can be a powerful force for mobilisation and change in the countryside. I hope that this project demonstrates this possibility.

There is no doubt that the Hokianga is perceived is 'different' to the rest of New Zealand. Countless times I was told, 'Oh it's different up there', or, they

have rules of their own, you know', or, 'What are you working up there for? You must be mad!' These 'common-sense' and 'common-knowledge' perceptions of the Hokianga intrigued me. Why was the Hokianga 'different? How was it different? When I tried to get at these questions, it always came back to the fact that Hokianga was perceived as a rural area, left 'wild', inhospitable in large parts, with a predominantly Maori population³. I examine these notions at length in Chapters 4, 5 and 6, where I consider discursive formations of otherness in terms of rurality at the local level in the Hokianga.

Otherness and disease.

Discourses of illness (and 'race' and 'rurality') are essentially discourses of otherness because their subjects are invariably viewed as threatening in some way, ultimately becoming marginalised in society as a result. For example, medical discourse has been influential in the ways in which illness tends to be perceived. One of the most common ways is as a dismaying loss of control that results in us becoming the other. This has had serious consequences for the ways in which diseases and other stigmatised conditions have been experienced. Through medical discourse, sexually transmitted diseases for example, have been seen as a combination of sexual deviance and disease as deviance which has doubly stigmatised the sufferer. Moral fears of contagion in the nineteenth

³Imperial science placed colonized people such as Maori at the bottom of a racial hierarchy, with white people at the top. This was because colonised peoples led a 'primitive' and 'uncivilised' existence. They were therefore closer to nature. And if they were a part of nature, they were less human and therefore had to be lower down the racial hierarchy (ibid). I return to the idea of 'race' and otherness later in this chapter and consider the Maori experience of this in detail, in Chapter 3.

century deemed the poor and the insane as unhealthy; medical fear of contagion and madness exacerbated the power of science to define conditions and treat them accordingly. In the same way today, through medical discourse, HIV/AIDS for example is associated with certain stereotypical, 'dangerous' groups, for example the gay population or IV drug users (Crawford 1994; Glick Schiller et al 1994).

Throughout the eighteenth and nineteenth centuries, the rise of the medical profession gave doctors tremendous power to define and order the worlds of human illness. The taxonomic system applied to disease categories was based along the same scientific, Linnaen lines as other 'natural histories', from the study of insects to the study of the worlds 'races'. These medical definitions rapidly took their place in an everyday reality; rarely were they questioned or challenged. They soon became taken-for-granted concepts that were considered not only fixed, but also common-sensical. Nowhere can this be more clearly seen than in the discourses of madness. Gilman (1985) argues that the most powerful model of pathological difference (i.e. perceived and real differences of ill bodies as compared to healthy ones) is that of mental illness. Mental illness, he asserts, is the ultimate loss of control over the self. It is this loss of control that is deeply embedded within notions of the other. Linked with notions of madness⁴ is the loss of ('sensible') language, for example, popular perceptions of insanity include demented rantings and ravings. Foucault (1967)

⁴Following Parr and Philo (1995), I chose to use the word 'madness' rather than 'mental illness' as a way of reappropriating a word that is often used in derogatory ways, and as a means of distancing myself from medical accounts of mental illness.

has shown how concepts of madness have changed over time. In the Middle Ages, for instance, lunacy was considered part of everyday life, and people who were mad were free to walk the streets. Gradually, however, these people were seen to be a threat: asylums were built and segregation of the insane became the norm. Much of this change in attitude can be attributed to theoretical developments - and fashions - in medical discourse. Madness became enclosed in a pathology of medical and moral perceptions which laid the fundamental bases on which madness came to be seen. Medical discourse remains key to understanding late twentieth century madness, since it is medical discourse that defines the problem and sets the 'normal' standards. I am not disputing whether something called 'madness' exists but rather that the function of the *idea* of mental illness, within our systems of representations, shapes our ideas about seeing the insane. In other words, far from being a neutral science, medicine and its discourses are implicated in the way contemporary medical problems are perceived and dealt with. Medical representations of the mentally ill, (particularly) in the media are crucial to how they see and feel about themselves. Through the discourses of medicine and media, problems and their solutions become defined for the mentally ill. Control of the issue is taken over by medicine and medical discourses. This enables a distancing, controlling and ordering effect to become established, creating an 'Us' and 'Them' type of modus operandi which is, of course, precisely what creates others in the first place.

In the same way, medical discourse teaches ill people how to behave, for example lepers learn to be lepers (Waxler 1981). 'Learning to know' how to have a disease is often done through negotiation with friends and relations as

well as through the treatment system. The ideology surrounding these types of stigmatised disorders provides a map to 'know how' to have the illness. It is therefore crucial to look at the social and cultural contexts within which diseases exist. If that aspect is neglected, then much of our understanding and compassion will become lost. Diseases have symptoms which get turned into facts with social meanings, and these have significant consequences for the sick person in terms of social labelling and the stress problems that ensue. The social distancing effects of diseases in terms of stigmatising is just one of the ways that those with the condition become othered. Another variant appears through aesthetics. It has been argued that society sees many conditions in aesthetic terms and that our discourse about the ugly is also our discourse about disease (Gilman 1988: 231). Diseases which disfigure, such as leprosy or AIDS/ARC (usually through Kaposi sarcoma) are therefore especially distanced from those not affected, as opposed to diseases which do not disfigure.

Otherness and 'race'/ethnicity.

Medical discourse has thus profoundly influenced our ideas about people with illness, and in a similar fashion, the discourses of 'race'/ethnicity have done much to shape our ideas about people with a different skin colour from our own. This is surely one of the most common forms of othering and comes about when humans are considered deviant because of their colour, often described in terms of 'race' (Ashcroft et al 1995; Barker 1985; Fanon 1992; Gilman 1985; Gould 1981; Hall 1992, 1992a, 1995; Said 1978; 1993; Sardar et al 1993; Spoonley 1988; Young 1992, 1995). Although the scientific concept of 'race' has been largely discredited as a category for analysis, in terms of racist practices, the

effects of this actual classification remain very real. Some of the underlying assumptions of racial otherness are sketched out below, describing how this process took hold in the European (and from the nineteenth century - the English) mind to the extent that it is still produced and reproduced today⁵. This brief account illustrates that even though science or academic opinions change over time, there is a time-lag before these new ideas become entrenched in the attitudes of the general population. As a result, although some ideas may have been challenged for a number of years, they still retain a prominent place in the popular (and common-sense) imagination.

In order to understand how concepts of race and skin colour have assumed a hierarchy that has become fixed in the Western mind, it is helpful to look at the history of 'race' and otherness. Sardar et al (1993: 26) have argued that notions of otherness were inherited from classical Greece where there was an acknowledged separateness from other people. This difference was established primarily through language - for the Greeks, the tool of reason. The key sign of persons less civilised than themselves was the inability to speak Greek⁶. This was a negative human condition: if someone couldn't speak Greek, they had no faculty of reason and therefore a poorly developed intellect. By medieval times, an iconography of otherness was firmly established. These ideas were direct transmissions of ideas that had originated with the Greeks. In

⁵This is not necessarily deliberate. Many racist acts and conventions are done without people even realizing they are essentially racist acts.

⁶The word barbarian comes from the Greek word *barbaroi* which means babblers, that is, a non-speaker of Greek.

addition, specific concepts of 'wilderness' had also developed, and myths of others who lived in the wilderness were often enough to stop people venturing into it. Influential cultural and intellectual texts such as the Hereford Map reinforced these notions, depicting strange beings with deformed limbs and sensory organs living in exotic locations. For those who had not travelled far, these must have been terrifying images. But medieval conventions of knowing changed rapidly post Columbus. He and his contemporaries were not new to the process of constructing or inventing others, but the 'discovery' of the 'New World' rewrote intellectual knowledge, and the construction of others became a global project (Hall 1992a; Sardar 1993: 40). With the colonial encounter, reports from around the world constructed a host of menial others, defining and directing a process forming a servile 'Them' and an advanced European 'Us' (Duncan 1993a; Jewitt 1995; Mitchell 1988; Said 1978; Young 1995). This hierarchy meant that imagined moral and racial superiority interacted closely with political domination and imperialism (highlighting the contextual and intertextual nature of discourses and their effects). Miles (1989) has argued that racism is in large part intertwined with the history of colonialism, where capitalist expansion led to colonisation in various areas of the world, and British perceptions of colonised peoples were structured by pre-existing racist ideologies. Racist discourse became woven into social, political and economic practices in order to justify and perpetuate exploitation and inequality.

The word 'race' came into common parlance in English in the sixteenth century, where it was seen as *lineage* up to the eighteenth century. 'Racial' came into English parlance in the mid-nineteenth century (Williams 1988: 248). There was an influential and prevailing opinion in the natural existence of 'race' in the

nineteenth century, where it was seen as immutable and fixed. Each race could therefore be defined by its unique biological and cultural characteristics. Influenced by Social Darwinism, ideas of evolution as a competitive struggle for existence and survival of the fittest *extended* from its original use, that is the relation *between* species, to social and political conflicts *within* one species. In the name of 'science', 'experts' began to search for regularities and differences within and between populations. By defining racial characteristics through skull measurements, facial angles, brain sizes etc., the emphasis on classification of humans through types and species became an important facet of scientific enquiry (Gould 1981; Jackson 1992). In relation to human 'races' this mode of thinking took the form of eugenics, a word introduced by Galton in 1883. From Greek roots, it connoted a sense of production of fine offspring. In some fields of nineteenth and twentieth century eugenics, class and racial superiority were widely circulated as categories for scientific analysis. Scientific evidence of variable heredity mixed with, and was often overridden by, pre-scientific ideas of 'pure racial stocks' and of the inheritance of culturally acquired characteristics.

The mixing of contemporary and antecedent scientific ideas spilled over into conventional concerns of the day. Victorians represented and used 'common-sense' descriptions of groups as biological species and types (Young 1995). These conceits extended not only to people with different skin colours, but also to England's own 'internal' others, such as the Celts. Yet there was never any conclusive agreement on the best typologies by which to classify different 'races' (Anderson 1991: 11). It seems, however, that skin colour was/is the easiest and most commonly used. Although 'scientific racism' has since been

largely discredited, its legacy is still with us and is prevalent in common sense assumptions about 'races' and the differences that exist therein. An example of this can be seen in a common British conviction, that people of African descent make better athletes than white people.

Images of others are therefore often constituted by and represented by colonialism which is itself situated in specific historical and geographical relations of dominance. Authors have argued that ideas such as Indian (Clifton 1990; Crosby 1991), Chinese (Anderson 1987, 1988, 1991), or Oriental (Said 1978) were originally ideas that belonged to a white European cultural tradition. Said (1978, 1993) has developed this further, demonstrating the effect to which representations of 'other' cultures reflect the 'domestic' concerns of their author's own society, rather than providing a faithful portrait of those they claim to represent. Wetherall and Potter (1989: 217) have argued that the racialisation of groups is just one 'node' in the ideological pattern which sustains and maintains the pattern of power relations. Yet, with few exceptions (e.g. Anderson 1987, 1988, 1991; Huggins et. al. 1995; Jackson 1992), geographers have shown little critical interest in turning their analytical gaze onto their own society's constructions of cultural difference, or applying a comparative perspective to their own culture as well as to those of more 'exotic' societies overseas.

The notion that we socially construct our view of others has led to a questioning of 'race' as a viable category for analysis and indeed Jackson has argued that 'race' has no explanatory value and serves 'little if any analytical purpose' (1987: 6, see also Fryer 1988: xii). I would agree with Jackson's

assertion, that 'race' is fundamentally a social construction rather than a natural division of humankind. The process of racialisation should be situated in history and society - not in biology and nature (Anderson 1991). But I also think because this construction has been so enduring, and that the reality of the outcomes has been so harsh, we should study the conditions and processes that have created these outcomes. This may help us make sense of why it is, that to a greater or lesser extent, it continues to this day. As I have mentioned, although the classificatory scheme of race as a category for analysis is not a useful one, there are nevertheless some very concrete effects of this social construction. Anderson (1987, 1988, 1991) has demonstrated this for the Chinese in Vancouver, where local opinion on things 'Chinese' was mediated largely through the local press and certain spatial practices, such as marginalising Chinatown. The culturally ascribed labels of 'Chinese' and 'Chinatown' were given to the Chinese community by the (dominant) white community. Moreover, Anderson argues that it was that community, rather than the Chinese, who conferred identity on the Chinese and the area in which they lived. A similar process operated for Canada's native population. Today, images of Native Americans as drunk and living on Skid Row are as prevalent as images of them in a tepee with a peace pipe (Clifton 1990; Francis 1992). Similar stereotypes of Maori also exist, in particular that they take up disproportionate amounts of health and welfare services and that they make up the vast majority of offenders. I discuss this issue further in Chapter 3.

The field of postcolonial studies has done much to revise our ideas about otherness in terms of 'race'. Postcolonialism has been described as 'a movement among artists and intellectuals that challenges the impact of imperialism on

non-western cultures, aiming to 'decolonize the mind' (Jackson 1994: 465). Crush (1994: 342) argues that 'decolonization' refers to two things: firstly, the need to disconnect from European ways of thinking and to develop indigenous ways of thinking; and secondly the need to break the boundaries between campus and community. Other key ideas of postcolonialism include opposing the ethnocentrism of the dominant white culture, a scepticism of 'totalising discourse' (Crush 1994: 334), and the deconstruction and decolonization of western intellectual traditions. Postcolonial writings have developed a radical potential through the writings of Spivak (1990, 1995), who is the best known member of India's subaltern studies group. This group, and other postcolonial authors call for a recovery of lost historical voices, particularly those of women (Jackson 1994: 604), calling for marginalised, oppressed and dominated voices to be heard but without distortion. (This in itself is problematic and extremely difficult to achieve.) Postcolonialists in general, and the subaltern studies project in particular, aim to undermine elite and ruling class versions of the past (and by extension, the present) by a process of deconstruction and subversion.

Geographers are increasingly attentive to postcolonial writings. Feminist geographers, for example are in the process of examining the differences in the construction of gender relations across 'races', ethnicities, religions, sexual orientations and nationalities, as well as how relations of subordination and difference affect women's lives (McDowell 1991). Geographers are also drawing on a wider range of social and cultural theory, including poststructuralism and psychoanalysis, in order to deepen their understandings about how identities are created and displayed (Nast and Pile 1998; Pile 1996; Pile and Thrift 1995). In addition, postcolonial writings are far removed from

objectivist, scientific methodology; they critique abstract and universal models of the human subject and society, supporting instead the notion of partial and situated knowledges (Haraway 1991; Pratt 1994: 195). Postcolonial literatures may thus be useful interpretative tools for this study, although I am aware of the potential difficulties involved. Their use does not automatically disconnect me from European ways of thinking. However, a thorough contextualisation in the New Zealand situation, whilst avoiding the perils of domestic isolation, should go some way to circumvent this potential criticism.

Discourses of otherness: the racialisation of disease.

In a fascinating set of essays, Sander Gilman (1985) examines three forms of otherness that have been prevalent throughout history. He chooses illness, 'race' and sexuality because, he argues, 'these are labels that have been given to broad characteristics essential to definitions of the self at various points in history' (1985 p. 23)⁷. In terms of sickness, Gilman points out that we construct illness as other because of our awareness of the human organism's fragility. This includes not only the human body's mortality, but also susceptibility to disease, corruption and alteration - in other words, a fear of loss of control over one's body. All societies otherise in terms of sickness and health, but exactly where the line is drawn between 'good' (healthy) and 'bad' (ill) is time-, place- and culture- specific. It is this line, however, drawn between 'good' and 'bad', that enables metaphors of illness to have such power. Sontag (1978) for example has shown how the metaphors of 'tuberculosis' and 'cancer' in the

⁷For excellent colonial histories of 'race' gender and sexuality see McClintock 1995 and Young 1995.

last two centuries have functioned as central markers for pathological difference. The metaphors attached to these conditions 'imply living processes of a particularly resonant and horrid kind' (p. 9). Both these diseases attain their status because of their essentially mysterious pathologies. The mystery surrounding these conditions was and is enough to make them feared and morally if not literally contagious. By using metaphors, the experience of illness and corruption - which could potentially happen to the Self - becomes projected onto others, and it is then the outside world which appears as corrupt and corrupting, polluted and polluting (Gilman 1985: 23).

Fear of disease is therefore projected onto certain sections of society. Often, these sections are already othered in additional ways such as gender or 'race'. The case of New Zealand is no exception, where Maori have been pushed into an inferior position and progressively othered since the arrival of Europeans. Maori health cannot be separated from their historical and contemporary experiences in New Zealand, where history has shown a tendency to build and reinforce a Pakeha (European) identity at their expense (Pomare 1995: 141). In the past, Maori have been stereotyped as disease-carriers; today discourses of disease suggest that Maori are much more unhealthy than Pakeha. Throughout the nineteenth century, the Maori population decreased rapidly (Crosby 1986; Fryer 1988; Pool 1991), so that by the 1880s there was a widespread belief they would become extinct⁸. The Wellington Provincial

⁸Before the British invasion, the Maori population was estimated at between 125,000 and 175,000. By 1900, it was nearer 45,000. This decline was partly due to warfare and partly due to disease. In 1854 alone, for example, 4000 Maori died of measles. In the late 1930s, Maori death rate was 24.31 per thousand population; the Pakeha rate was 9.71 per thousand. The infant mortality rate for

Superintendent, Dr. Isaac Featherston, echoed liberal European attitudes when he spoke of the obligation to 'smooth the pillow of a dying race' (Pool 1991: 28; King 1984: 73). The arrival of the Pakeha not only brought disease, conflict and dispossession, but also caused the destruction of belief and family systems (Durie 1994: 6; Hiemstra 1994). These catastrophes undermined Maori cultural identity and institutions such as land, language and family, which were and still are vital for good health. The decimation of the Maori population set in motion the popular Victorian discourse that Maori were vastly inferior, both morally and physically to European settlers, and therefore more likely to carry diseases (Fryer 1988). Certain conditions were therefore assigned to the Maori population, for example, tuberculosis, alcoholism and destitution. In 1911, for example, the Auckland health officer whose catchment area held the majority of the Maori population, said Maori health should be of concern to Europeans only because the unchecked spread of Maori diseases could eventually lead to Europeans contracting them. He believed that 'As matters stand, the Native race is a menace to the well being of the European' (quoted in King 1984: 75). The real reason, of course was that Maori had no immunity to infectious diseases and they were being denied access to cultural identities and institutions. But the legacy of that discourse remains; many New Zealanders of European extraction still hold racist assumptions, and the undermining of cultural institutions produced effects that are still seen in Maori-Pakeha health differentials today

Maori was 4 times greater than that of Pakeha. Examples of Maori: Pakeha ratios of disease incidence include influenza 5:1; bronchitis 3:1; pneumonia 4:1; and typhoid 39:1 (Fryer 1988: 42; Pool 1991).

(Baskett 1995; Costello 1994: 23; Hiemstra 1994; Pomare et al 1980, 1995; Shipley 1996).

Otherness and the body.

The body is the prime site where, and through which, identity is constructed (Grosz 1994; Shilling 1993, 1997; Turner 1992; Woodward 1997; see also Chapter 8). This has important implications for questions of otherness and marginalisation, because although literatures may remain abstract and theoretical, it is real people who have experienced the reality of being an other. Franz Fanon described this as the 'fact of blackness' where black bodies were/are seen as evil, hated and ugly (1992). Moreover, this 'fact of blackness' was and is inescapable. It is thus bodies on which the experiences of colonialism and postcolonialism (and health and ethnicity) are inscribed. The body is thus a site for socio-political struggle and cultural change (Lancaster and Leonardo 1997; Pile 1996, ; Pile and Nast 1998; Pile and Thrift 1995; Rodaway 1994: 7; Weitz 1998; Women and Geography Study Group 1997). As such, a theoretical and practical examination of the body is necessary for this project. This is one empirically under-researched area where socio-cultural dimensions of health and illness for real people in real life can be explored. Until recently, social and political theory has ignored the human body, instead placing stress on social structures and/or individual subjectivity. There has been little room for an appraisal of where the corporeality of lived bodies fitted in. But the rise of various social movements in the late twentieth century, including continental poststructuralism, third-wave feminism and the growth of consumer culture have all developed challenging new ways of theorising the body. In addition, Shilling

(1993) has argued that the more we have been able to control our bodies, the greater our uncertainty has become over exactly what constitutes an individual's body and what is 'natural' about the body. For example, the advent of in vitro fertilisation and cloning programmes have raised new questions of identity, ownership and ethics surrounding the bodies involved. Thus in one sense, bodies are not defined and fixed entities, but have shifting boundaries. That is not to say we are not constrained by our own corporeality, but that as technology and therefore power/knowledge constellations change, so too does the potential 'fixedness' of our bodies.

The human body is ultimately the subject of all research that is directed to analysing social dimensions of medicine, health and illness (Lupton 1994: 20). Yet many studies within the social sciences relegate this proposition to an unstated, unproblematic assumption. The body has become a taken-for-granted 'fact' that needs no further analysis. It is easy to ignore the importance of the body simply because it is such a taken-for-granted part of ourselves. Yet if bodies are the essence of any social analysis, they need to be closely examined at both theoretical and empirical levels. In the thesis I explore socio-cultural dimensions of health and illness and how these are played out on real bodies in real life. This is an attempt to understand firstly, how people come to understand and make sense of these issues, and secondly, to contribute to critical policy debates. It is hoped that this will highlight new ways in which we can think about health issues from a geographic perspective.

Scheper-Hughes and Lock (1987: 8) identify three overlapping levels of analysis when theorising the body. The first of these is the individual body - the

lived experience of the body-self, and how we view our own and others bodies. This perspective has been explored most notably by Merleau-Ponty (1962). From his phenomenological perspective, he regards the body as an intentional agent, in which sickness must be recognised as a lived-body experience rather than cellular acorporeal phenomena. The phenomenological approach also accounts for the emotional dimensions of physical disorders, and authors such as Toombs (1992) have offered phenomenological accounts of the lived experience of disability. The phenomenological notion of the lived body 'provides important insights into the profound disruptions of space and time that are an integral element of changed physical capacities such as loss of mobility' (ibid.).

The second level of analysis when theorising the body is the level of the social body, where symbolic representational uses of the body are used in conceptualising nature, society and culture. Phrases such as a 'sick society' or the 'head of state' come into this category. This level of analysis relies on structural theoretical perspectives. (Lupton 1994: 22; Scheper-Hughes and Lock 1987: 8).

A third level of theoretical analysis conceptualises the body from a poststructuralist perspective. This way of thinking has profoundly influenced how bodies can be theorised. In the same way that texts and discourses are seen as unstable, poststructuralists also see both subjectivity and the body as being continually in flux. Rather than the human body being conceptualised as a given, fixed reality, it is now seen as a product of certain kinds of knowledge which are subject to change through time and space (Featherstone et al 1991; Foucault 1981; Jackson and Penrose 1993: 14). Bodies therefore possess a spatiality in

that they are the site where ‘constellations of power-knowledge are inscribed...through which particular subject-positions are constituted’ (Gregory 1994: 584). Bodies are not only shaped by social relationships, but enter into the construction of these relationships in a way that is modified by historical, geographical, political and cultural circumstances. Perceptions of the body are mediated through language and the surrounding culture, located within competing discourses of the era. This means how and what we think about bodies has changed throughout history (Jacobus 1990: 4). For example in medieval times, it was considered sacrilege to open up a corpse and examine its internal organs, nowadays in ‘western’ societies, this no longer tends to be the case. (Sawday 1995). In the same vein, what is considered ugly or beautiful or diseased varies from place to place and throughout time. Societies construct bodies in terms of shaping (or misshaping) them and deciding what is desirable or undesirable. In addition, body image is important in establishing identity (Cohen 1993: 120), and perceptions of our own bodies are also culturally controlled (Bordo 1990; Martin 1990). Thus in the South Pacific, for example, cultural shaping of the human body means that obesity is not seen as ugly or unhealthy, but as a display of wealth and beauty. By contrast, in British society, obesity is seen as an undesirable condition usually brought about by lack of self-restraint.

A poststructural approach views the body not solely as a given reality, but as the product of certain kinds of knowledge which are subject to change. Thus the body is conceived as a set of practices or ‘body techniques’ which represent and regulate bodies in time and space. Bodies are not shaped simply by social relationships, but they enter into the construction of those relationships.

They are both helped and hindered by historical, cultural and social factors. From a poststructural viewpoint, biopolitics of the body are of central interest. This is where the state controls, regulates and surveys the conduct of bodies at individual and group levels in order to maintain social stability (Armstrong 1983, 1987; Foucault 1976, 1977; Lupton 1994: 21-22; Turner 1982a, 1992). The ways in which the state undertakes surveillance and control of bodies, and how eventually those bodies self-regulate and discipline themselves forms a large portion of contemporary poststructural studies in medical sociology (Lupton 1994: 23). Frank (1990: 134) describes four main ways of theorising how bodies, and the spaces between them can be regulated into a 'somatic society' (Turner 1992), where the body in modern social systems has become the principal field of cultural and political activities. The four typologies that Frank has suggested necessarily have fluid boundaries. They are the medicalised body; the sexual body; the disciplined body; and the talking body. Although the first type is most obviously related to this project, all four examples are bound up with the medical system and with people's health experiences.

Nietzsche, Deleuze and Foucault have made important contributions to the ways in which bodies are theorised from a poststructural perspective. Nietzsche sees knowledge as functional for the body. The potential to acquire knowledge is the most important 'organ' of the human body (Lash 1991: 270). Nietzsche argues that bodies are systems of forces that are connected by a common mode of nutrition. Body organs are important for him, especially the sense organs. They are what interpret the world around us so that any species will see 'truth' as what has enabled them to expand its reproduction. All bodies are driven by their basic instinct for their own expanded production. This

reproduction takes place depending on a body's struggle with other external bodies and on relations of force between struggling entities (organs, structures, values) within the body. According to Nietzsche, beliefs in subject or truth are not objective but we hold them insofar as they function towards the expanded reproduction of our bodies. However, these beliefs lead us to a false view of a stable external world. This view has been rejected by some (for example see Lash 1991) who argue that we do not experience our bodies in this way.

Deleuze has gone further in thinking out a notion of the body than the other French post-structuralist theorists (Lash 1991: 268-269). His desiring machines are based on biological lines. But his view of the body is not at all biological as Nietzsche's is. Deleuze refers to a 'body without organs,' in an effort to explain how we do not and should not perceive and experience our bodies in terms of their biological organisation (Deleuze and Guattari 1983; Fox 1993). Deleuze sees the convergence of this non-organic view of the body with Merleau-Ponty's 'lived body'. But he does not want to attribute the unity, coherence and intentionality to the body that Merleau-Ponty does. Instead, Deleuze sees the body as the surface of intersection between libidinal forces and external social forces, where libido is socially structured by the global characteristics of the social, acting through the mediation of significant groups such as the family. It is the interplay of these forces that gives the body its shape and specific qualities.

In contrast, Foucault's focus on 'the body' has been claimed to be his 'major response to Derrida's textualism: a demonstration in counterpoint' (Boyne and Rattansi 1990: 11). Foucault's bodies are cross-cut by the power of

knowledge and by the use of knowledge by power (Lupton 1994: 23). Foucault documents this using various examples, most notably the prison system (1977) and the medical system (1976). In *Discipline and Punish*, he describes the change over from inscribing punishment on the bodies of offenders as public ritual directly affecting the body, to a new system where the body has become the focal point for the exercise of disciplinary power. However, in the new system, power or punishment does not act directly on the body, but through the disciplinary gaze which acts to produce a 'bad conscience'. This then becomes attached to bodies. In *Birth of the Clinic*, Foucault describes an 'anatomical atlas', which is the human body as constituted by the scientific medical gaze. By the late 20th century, this conception of the body has become thoroughly normalised through a biomedical framework; there is little recognition that there are other ways of conceiving the body and its illnesses. This is exemplary of the effects of discourses. In both examples, bodies are acted upon discursively, and constituted by institutional settings (Lash 1991: 259). These institutions, for example, the penal system, medicine, education and psychiatry define the limits of human behaviour and record its activities in meticulous detail. Those with bodies that violate the boundaries get punished or treated somehow, so that bodies can once again become rendered politically and economically useful.

These conceptions of the body show that in different times and places, different understandings of the body prevail. This is an important and as yet unexplored region for medical geography; but after all, presumably medical geographers need to be aware that such variations exist. They also show how bodies are the sites of power and knowledge, and that these are also subject to change through time and space. Most discourses of the other focus around the

body in some way, be it colour, gender or sexuality for example. Identity is intimately linked with space and place, and once an identity is seen as spoiled, as othered, the damage is often irreversible. Reflecting on the social constructions of others and the various conceptions of the body, reminds me that these identities are not fixed and immutable categories, but constantly shifting. And this means that there is space for shifts towards more positive viewpoints of difference in the future. Studies of multiple otherness may be one formative step towards these future outlooks.

In more practical terms, for my own work, it is necessary to be aware that Maori people often hold very different views of their body than Pakeha. I had to learn quickly what was and what was not appropriate behaviour in Maori households. For example, it would have been a big mistake to touch a Maori persons' head, whether adult or child; and I had to remember not to look people directly in the eye. In talking about matters medical, much of the conversation had to proceed in Maori to save acute embarrassment - the body is a most sacred and personal part of Maori life, and definitely not the sort of thing one would talk to strangers about. Discourses of the body and race/ethnicity were closely linked with issues of illness and otherness and I describe these links in more detail in Chapters 6, 7 and 8.

2.4. CONCLUSIONS.

This project draws on certain strands of contemporary social theories, but at the same time remains very practical. This chapter draws from the literatures of 'discourse', 'otherness', and the body. Together, these three themes

form the theoretical underpinnings of the thesis. In examining these topics, I am aware that I have oversimplified the links between and within them, and the wider debates of postmodernism, poststructuralism and postcolonialism within which they are situated. These categories and sub-categories are not in any way mutually exclusive, but I have presented them in this particular way for clarity and ease of using.

To a greater or lesser extent, there are multiple discourses continuously shaping and reflecting reality. Thus there are different stories and versions of the same reality. For example, there are many discourses of health as well as numerous responses to various health initiatives. Examining discourses produces understandings of difference which go beyond conventional groupings of social attitudes, and interpreting discourses around one topic, for example health, might demonstrate how and why some discourses become more influential than others and how other discourses themselves become othered. Studying discourses of otherness, and other/othered discourses stresses the importance of discourse as opposed to “attitude” in understanding different health and health care experiences. Otherness is a social process of identity formation and discourses highlight the social processes of marginalisation and how group identities become othered. Although otherness in the thesis focuses on race/ethnicity and illness, gender, age, income and rurality are also relevant and are discussed more in Chapter 4. These are the theoretical underpinnings on which the thesis is based and I shall be returning to them throughout the rest of the thesis.

What relevance does this have for health research in general and this project in particular? Examining discourses of health and ethnicity has the potential to critically examine social constructions of disease, and the ways in which various cultures use notions of disease to define social boundaries. This should enable me to answer at least some of my research questions as outlined earlier, by examining both hegemonic and non-hegemonic discursive formations around issues of health and illness, as well as cultural difference. Investigating the discourses of 'race' and place might also be a way of understanding different health geographies. As yet, little work has examined the links between discourse, 'race'/ethnicity, health and the body, and the aim of this project is to connect rather than separate these diverse strands of inquiry. Throughout the thesis, I tease out some of these connections and theoretical ideas as they are played out in real life, for real people, in one area of New Zealand, the Hokianga. I begin this in the next Chapter, where I examine the particular New Zealand context. I then move on to discuss the Hokianga experience in more detail in Chapters 4, 6, 7 and 8.

CHAPTER 3. THE AOTEAROA/NEW ZEALAND CONTEXT.

3.1. INTRODUCTION.

Medical geographers are slowly beginning to explore new ways of seeing the world; the world in which we live and in which we are healthy or ill. With the knowledge that health cannot be understood with reference solely to biomedicine, these new perspectives incorporate a variety of questions and methodologies that allow situations to be properly contextualised. Contextualising a situation further clarifies the nexus of social relations within which people's lives are embedded, and this in turn may highlight hitherto unquestioned processes and patterns involved in health issues. I am particularly interested in social theory as a vehicle for analysing health issues, specifically whether certain facets of postcolonialism, postmodernism and poststructuralism might be useful in broadening our understandings and contextualisations of health. These, as yet, are largely unexplored issues from a medical geography perspective, and it is these issues that form the bulk of this thesis. But can European theoretical developments be gainfully employed in a New Zealand context? Peters et al argue that they can, provided they are not imposed, but are themselves thoroughly grounded in the New Zealand situation they are trying to explain, *and* provided they avoid the pitfalls of '...domestic insularity and overseas elitism', (1996: 22-30, the quote is from p. 24). In recognition that theory must be contextualised so as to accommodate the particular circumstances of different places, this chapter's purpose is to set the general context for the thesis by examining parts of the social context as they apply to

health issues. The aim is to provide a background for the underpinning themes outlined in Chapters 1 and 2, by looking at the specific New Zealand situation.

Health and health care are shaped by the larger social contexts within which they occur, and social contexts are characterised by the enduring relations of economic, ethnic, gender and political power (Fougere 1990: 148). An interest in the links between health and ethnicity makes New Zealand an exciting place to study, but it is neither practical nor necessary to provide a complete summary of the country's state of affairs. Instead, I offer a partial story that explores issues most pertinent to the project. The chapter therefore examines key health and ethnicity matters in New Zealand. This situates my study both within current New Zealand literatures and the contemporary social and political climate.

In framing the wider context for the project, I think it is also important to bring in my own story and explain why I chose New Zealand. In terms of my own situated knowledge and geographical imagination, I am a practising medical professional with wide health interests. I have always been interested in the histories and realities of the legacies of the British empire, and I am intrigued by the work that has been carried out under the guise of 'postcolonial studies'. It seems to be the case that in geography, many ethnicity and health studies focus on the status of immigrant peoples, be that forced or voluntary. I am interested in focusing on indigenous/aboriginal peoples as there is little literature on the subject of their health issues to date. My MA in Canada tried to focus on some of these ideas, examining the tortuous nexus of 'race', space and health in one small, predominantly native town in British Columbia. This has fuelled my

interest in the links between marginalisation (particularly aboriginal cultures), health and social life. New Zealand seemed an eminently suitable place to continue studying these ideas¹.

Many societies have diverse ethnic populations, often the legacy of a former imperial order. 'Culture' in these societies may be of a hybrid form, although the hegemonic strata of society's culture will dominate. It is within this context that the politics of 'race' place and health continue to change. What this means for different sections of the population depends on where they fit into the social order. The problems of studying connections between ethnicity and health can be seen as part of a critical epidemiology (Arnoux and Grace 1994; Jones and Moon 1987) that challenges western biomedicine as inappropriate for what amounts to sometimes large sections of a population. Because social factors are important in illness and death, and because biomedicine cannot account for these, new theoretical approaches are needed. They must acknowledge the importance of behaviour and lifestyles as well as recognise the chance interlinking of social, political and economic factors. New perspectives may be enhanced by the theoretical innovations I have outlined in Chapter 2, bringing a different perspective to culturally marginalised groups' health problems, as they themselves see them.

Investigating links between health and ethnicity poses certain difficulties, one of which is the vexed question of whether it is appropriate or

¹In addition, I was lucky enough to be awarded a Leverhulme Study Abroad Scholarship which solved many logistical and financial problems for me. I am very grateful for their support during my year in New Zealand.

legitimate for Pakeha to write about Maori issues. Clearly, there are some things that would be inappropriate for Pakeha to write about, for example what it means to be Maori. But certain topics, in my opinion, should be addressed because they affect both Maori and Pakeha. This thesis is not a dissertation about Maori people *per se*, but it *is* about health issues in an area that happens to be predominantly Maori. Entering a research situation in which the majority of people are Maori demands that I should at least be aware of some of the current debates. Because of this, it is important to include contextual matters that affect the lives of *all* people in the study, Maori and Pakeha alike. The chapter therefore examines contextualising factors such as ‘race’ and ethnicity in New Zealand, the Treaty of Waitangi, differing conceptions of health, and cultural safety. These issues form the background to the study, enabling me to place it within the contemporary New Zealand setting.

3.2: HEALTH CARE PROVISION IN NEW ZEALAND.

A former British colony, today New Zealand has closer ties with nearer countries, such as Australia and the islands of the south west Pacific (Pawson and Kearns 1992: 283). It has a reputation as a ‘social laboratory’ introducing innovative legislation such as the Old Age Pensions Act 1898, the enfranchisement of women in 1893 and the 1938 Social Security Act. Yet although New Zealand is often perceived as an egalitarian society, by the late 1980s, 10% of its population owned half the wealth of the country, and 1 million people lived below the poverty line (Considine 1989: 172). New Right economic policies of the 1980s have not only affected the distribution of wealth

in New Zealand but also initiated new ideas and mechanisms for the provision of health care.

From an international perspective, New Zealand has been outward-looking in terms of its health services (Salmond 1994: 189) and at the cutting edge of health system development. The golden years for New Zealand's health service came after World War 2, when social security and health legislation passed by the first Labour Government established New Zealand's reputation as a leader in socialised medicine. Health benefits could be provided equally to all New Zealanders and by the early 1950s nobody had to pay directly to visit a general practitioner (Salmond 1994: 183).

Traditionally looking to the UK for ideas and innovation, more recently, New Zealand's health and economic policies have been profoundly influenced by the US (Salmond 1994: 190). Like other 'westernised' countries, New Zealand has seen a fundamental overhaul of the public health system in the 1980s and 1990s (Barnett and Barnett 1997). The upheaval stems from a series of crises and challenges that have occurred outside the health system over the last twenty years. A gradual decline in the competitiveness of New Zealand's agricultural sector resulted in many financial problems, which in turn have put increasing financial pressure on the welfare sector. Since the 1960s New Zealand has become an increasingly fragmented country with wide social and spatial divisions (Thorns 1988). In an attempt to alleviate these problems, the newly elected National (Conservative) Government of 1975 devised a number of strategies to stabilise the weakening economy. These included the deregulation of transport, taxation reform, some tariff reduction, and the establishment of

large energy producing projects designed to reduce dependence on imported fuels (Edlin 1984, quoted in Stubbs and Barnett 1991: 330). From 1984-1990 the Labour Party were in power. They introduced a programme of radical economic restructuring (Britton et al., 1992), although the welfare sector was left largely intact (Barnett and Barnett 1997). The previous direction of reforms was reversed by the introduction of sweeping plans that deregulated the market and privatised state sector public enterprises. It was believed that this would decrease the burden on the national debt, however, these actions turned stagnation into depression. The result was that many industries had to close and unemployment reached record levels. In the event, the drive to economise was a major factor in the restructuring of the health service.

In July 1991, the recently elected National Government sketched out its vision of a radically reconfigured health service. Following a Health Services Taskforce review, it was recommended that the old health system be dismantled and a new one set up. The new health system would create a purchaser/provider split, and was to be based on notions of 'managed competition' (Fougere 1994: 107). It was underpinned by New Right policies such as competition between private and public funders², and private and public providers, of health care. Under the new system, purchasers would buy care from providers. The purchasers are the Regional Health Authorities (RHAs). New Zealand is currently divided into 4 geographic regions, each supported by a Regional

²So far, the the introduction of multiple, competitive funders has yet to happen. Initially it was envisaged that people dissatisfied with the Regional Health Authority's performance could pull out of the scheme and enter a Health Care Plan, which would be a kind of health insurance scheme.

Health Authority (See Map 2 p. 77). The RHAs are responsible for purchasing all publicly funded personal health and most disability support services for the people in their regions (Ministry of Health nd: 4). They are also responsible for ensuring access to primary and secondary health care. They buy services for their population from providers, - the agencies that supply health or disability support services. Providers can be either publicly owned institutions, private hospitals, or smaller individual providers, such as community trusts, GPs, midwives, and home care agencies, etc.. The largest publicly owned providers are the Crown Health Enterprises, commonly known as CHEs. Although they are owned by the state, they are expected to compete in the market with other providers (Barnett and Barnett 1997). There are 23 CHEs in the country, each is based around a public hospital. Providers can therefore be from the public, private or voluntary sectors. This means that the RHAs can buy packages of services from various providers in the area, tailored to suit the needs of a local or larger community, depending on the type of service being sought and the community's needs. The purchasing of services is then formalised in a contract between purchaser (the RHA) and provider (agency that delivers the service, for example, hospital or community trust).

The New Right policies implemented in the 1980s in New Zealand (and other places such as Great Britain, North America and Australia) were designed to produce market solutions to economic and social problems. Amongst other things, these policies included scaling down the activities of the welfare state and a return to laissez-faire policies (Shirley 1990: 139). The outcome is that professional health care in New Zealand is currently provided through a mix of public and private funding and provision (Fougere 1990: 158) although the

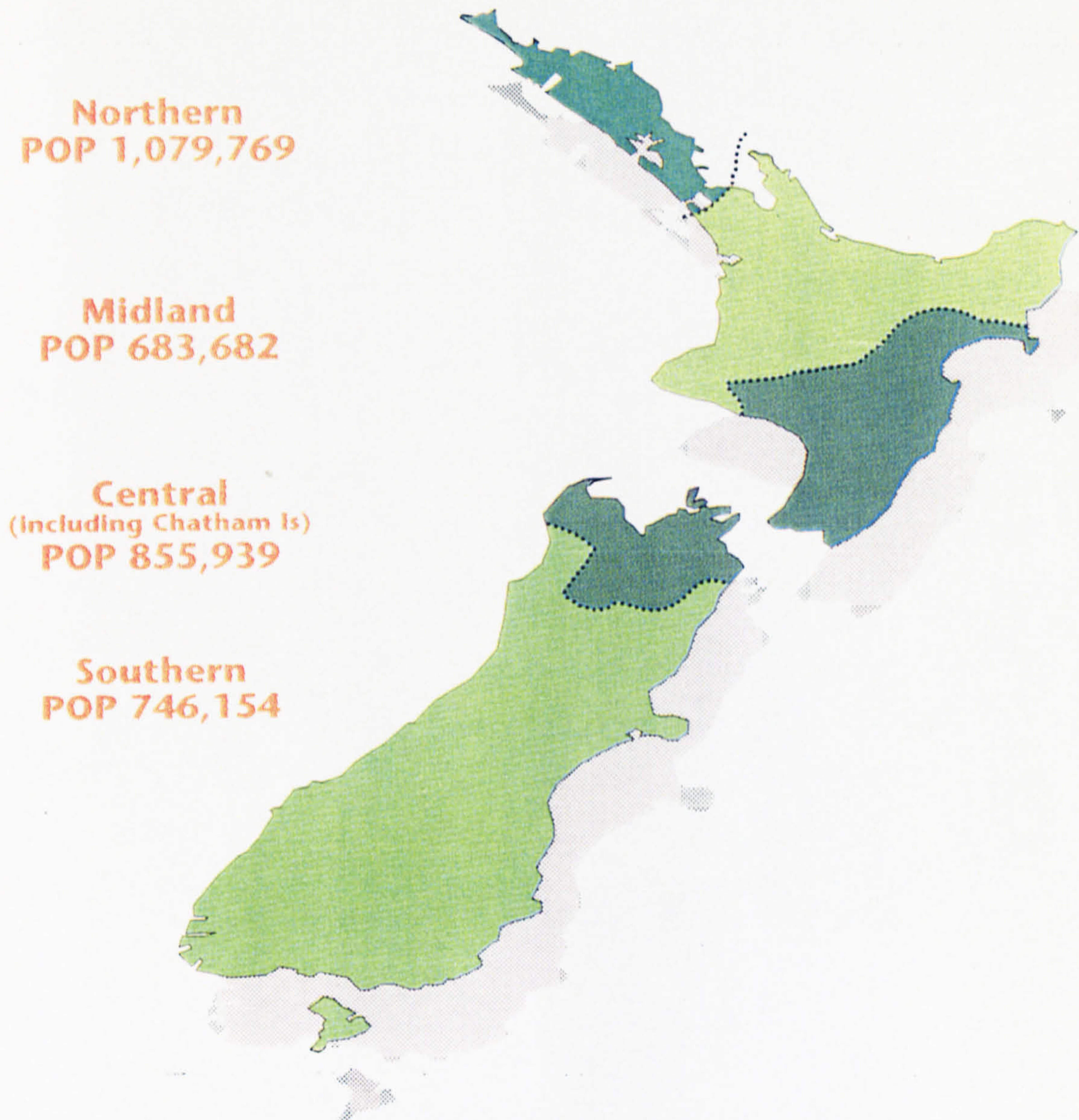
nature of this balance is a delicate question. The health system has therefore changed drastically in the last twenty years. In the 1980s, the service was publicly funded and serviced. By the 1990s, the purchasing and providing functions had been totally separated (Salmond 14/01/99: 185). This meant that private as well as public service providers could enter the market and bid for contracts from the purchaser of services (the Regional Health Authorities). Other changes included the restructuring of hospital boards into area health boards, the creation of basic performance contracts between the Minister of Health and the Area Health Boards, and the development of a contract system to draw general practitioners more directly into the public health system (Fougere 1994: 110).

In 1993, the Department of Social Welfare relinquished responsibility for Disability Support Services (DSS), and handed it over to the Ministry of Health. This was enacted by passing the Health and Disability Services Act, 1993. The key services covered by this new legislation were primary health care services, secondary health care services, disability support services and public health services. The act also incorporated the notion of performance based contracts between the government and the purchasers (the RHAs) of health and disability services. This was done so that the government could measure the quality and effectiveness of services in addition to what the RHAs were already doing. Disability Support Services are for people with a "...physical, sensory, intellectual, psychiatric or age-related disability" (Ministry of Health nd: 11). The new legislation brought funding together from previously diverse sources and placed it with the RHAs. The new legislation also made the RHAs solely responsible for purchasing services to support the independence of people with disabilities, in an attempt to devise a more integrated approach to social policy.

It was envisaged that better integration between the various government providers of health and welfare would help achieve an integrated package of income supports, health care and social assistance services for such people, and that improved delivery of disability support services would mean a person's needs were better matched to the most appropriate service.

In summary then, the current situation is this. RHAs are funded by central government. They purchase services for their regions. They do not provide services, they pay other providers to deliver them. The RHAs find out what services are required, by consulting on needs and priorities with local communities and other interested groups. They formulate purchasing plans and negotiate with service providers such as Crown Health Enterprises or local community trusts. They formalise these purchasing plans through contracts. Amongst other things, the contracts specify the level of quantity and quality of services, the cost of a particular service or product, that the services meet agreed standards, and ensure that the providers are accountable for the public money they are paid. The idea is that by having many different providers, different needs can be met more successfully than under the old system.

MAP 2. REGIONAL HEALTH AUTHORITIES OF NEW ZEALAND.



(Source: Ministry of Health, nd.)

3.3: 'RACE' AND ETHNICITY IN NEW ZEALAND.

In late nineteenth century Britain, prevailing opinion held that the 'success' of colonisation was proof of an inherent superiority. In order to rationalise this notion, Britain looked primarily to racial hypotheses. These ideas travelled with colonists the world over, so that this process occurred not only in New Zealand, but everywhere colonisation took place. In New Zealand, two schools of racial thought came to be used to theoretically justify why Europeans would thrive and why Maori would become extinct. In the 1840s, polygenist racial determinists³ argued that 'race' was the key determinant of history. They believed racial conflict was inevitable and that the subordinate status of darker-skinned races was irreversible (Solomos and Back 1996; Young 1995). From the 1850s, evolutionist theories gained popularity. They held that Europeans survived at the expense of others through the inevitable struggle for existence. The work of Charles Darwin, especially the notion of 'survival of the fittest' influenced colonists' views. Darwin's theories helped scientifically justify European domination, the concomitant take over of land and the predicted extinction of the Maori. Thus the laws of nature prescribed the inevitable triumph of the British over Maori. Both polygenist and evolutionist theories alleged the 'darker races' would inevitably die out as a result of contact with whites, and both theories travelled to New Zealand.

³The polygenists believed that different 'racial' groups had different origins. Their theories were underpinned by the new racial theories in comparative anatomy and craniotomy in the US (Solomos and Back 1996: 35). Although this contradicted the widely accepted single origins of the human race (descent from Adam and Eve), they found ingenious ways around this problem (Young 1995: 9-13).

New Zealand did not witness a colonial interpretation of racial conflict, but a British Victorian one (Belich 1986: 330; Wetherall and Potter 1992: 124-125). Mulgan (1989: 36) claims that most of the colonisers were not consciously destructive or deliberately deceitful. He argues that colonial settlers held a sincere conviction in the superiority of their own civilisation and in their right to settle in a land which, appeared to them largely unoccupied and underdeveloped. In the same vein, Belich (1986: 321) has argued that Victorian ideas of race were more complicated and less intentionally malign than sometimes implied. He suggests that British expectations arose less from individual greed than from the racial and national attitudes that were part of the Victorian ethos. Many nineteenth century colonists considered Maori as 'wayward children' that could be 'civilised' into the norms of the now dominant culture (Pawson 1992: 26). When Europeans, including those in New Zealand, compared themselves to 'primitive' societies they perceived huge differences. One way these differences were explained was by invoking the 'higher mental faculties' (Belich 1986: 326). These included the competitive capitalist values of an enlightened and 'civilised' society. Maori were charged with a 'beastly communism', because their society was kinship based and they lacked an ethic of capital accumulation (Pawson 1992: 17). Unlike European society, social status was not judged by the amount of goods an individual had amassed, but by *mana*⁴. The most obvious supporters of the higher mental faculties thesis were

⁴In modern times, *mana* has various meanings and nuances. Broadly speaking it is social status that is earned or inherited. Barlow (1991: 61-62) describes four main aspects of *mana*. *Mana Atua* is the sacred power of the gods given to those who conform to sacred ritual and principles; *Mana Tupuna* is the authority and power inherited and sustained through successive generations of chiefs; *Mana Whenua* is the power connected with the (spiritual as well as literal) possession of lands; and *Mana Tangata* is the power and status earned by someone who has

the polygenists who assumed that non-Europeans lacked the higher mental faculties. These 'inveterate savages' (Stephenson (1896) quoted in Kiernan 1969: 262) were believed to belong to 'the lesser races', a position to which they were consigned for over a century. Maori were, however, assigned a higher place in the perceived 'order of races' than those such as Australian Aborigines, because the British respected their military expertise, cultural lifestyle and their interest in trade and literacy (Pawson 1992: 17). On the other hand, Belich (1986: 304) has suggested that the colonists respected Maori for the simple reason that if they didn't, they (the colonists) may well get killed. This did happen on occasion (King 1984). Maori viewed Pakeha society as egotistical, mercenary, greedy, uncaring about the extended family and disrespectful towards the dead (King 1984: 198).

The history of Maori society is not and never has been a coherent single entity (King 1984: 5; Walker 1992: 498). Pre-European New Zealanders identified themselves by *hapu* (sub-tribe), which were part of a larger *iwi* (tribe). Each *iwi* could trace its ancestry back to a single ancestor. Before Europeans arrived, the Maori world was made up of many different *hapu* which consisted of individual *whanau* (extended families) living together in communities. Identity lay not in being Maori, but through *whanau* and *hapu* affiliation. Whether the word and concept was used regularly in pre-European times is disputed (see for example Barlow 1991: 70; King 1984: 37; Mulgan 1989: 12), but it is generally agreed that the word was used extensively post-European

developed skills and knowledge in a given field such as warfare, or childcare.

contact⁵. However, Europeans in New Zealand believed that Maori were all the same. As a result, different tribal histories and traditions became erased. Most Europeans did not distinguish between different *iwi* and *hapu*, they were simply all 'Native', a word that was common also in official usage (King 1984: 74).

The New Zealand Wars were fought largely over land and were crucial in the development of New Zealand race relations (Belich 1986: 15; King 1984: 301). Maori resistance during these wars made a lasting impression on the British both in Britain and New Zealand. Maori came to be held in higher regard than indigenous peoples elsewhere and it has been claimed that this is why New Zealand race relations are so much better than Australia, America and Africa (Belich 1986: 299). The first major battle occurred in 1843 and from then on, European and Maori adhered to the two Maori principles of early race relations - a determination to uphold chiefly authority against arbitrary British interference and a desire for interaction with Europeans (Belich 1986: 30). This situation had disintegrated by the 1860s as the British came to dominate through the alienation of Maori land. By the turn of the century, Maori autonomy was a thing of the past and Maori increasingly withdrew from European contact.

The myth of harmonious race relations in New Zealand was underpinned by the fact that Maori were, until the mid-twentieth century, predominantly rural (Consedine 1989: 172; King 1984: 300; Pawson 1992: 24). Because Maori were isolated geographically, culturally and socially, race relations became a less dominant aspect of early twentieth century life than in the nineteenth. Their

⁵Maori means normal or ordinary, as opposed to Pakeha, a foriegner or a white New Zealander (Biggs 1990: 118; Barlow 1991: 87).

relative invisibility meant they received less government attention and for a long time, the official attitude was to ignore Maori (King 1984: 75). There were, in effect, two New Zealands, a Maori one and a Pakeha one (King 1984: 195). Various racist stereotypes and misconceptions emerged over time to explain the exclusion of Maori people from mainstream New Zealand. Postcards featuring rural Maori life in the early twentieth century circulated widely. Idealised scenes showed Maori as bumpkins content to live simple, rustic lives. Another, perhaps the most enduring, is the image of the Maori as a genial buffoon, an imprudent chap who made poor use of his land and therefore deserved to lose it (MacDonald 1990: 7). These kinds of (often contradictory) images depicted Maori as lazy and stupid, partial to manual and outdoor labour. The mocking representations suited the European New Zealander, and only in recent years have they been seriously challenged. But even today, Maori and Pacific Islanders are often negatively stereotyped, perceived as inferior 'races' who take up disproportionate shares of welfare services and making up the vast majority of offenders. They are frequently seen as violent and repeatedly breaking the law (Consedine 1989: 173). These clichés are perpetuated in the media (Spoonley 1990; 1994), particularly in the popular press. Headlines are often misleading, presenting Maori as angry protesters, and threatening the breakdown of law and order, for example, 'Gang aggression rising'⁶, 'Jail rate threatens Maori society'⁷, and 'Maori threat over collection'⁸.

⁶*New Zealand Herald*, November 6, 1995, Section One, Page 12.

⁷*New Zealand Herald*, January 31, 1996, Section One, Page 16.

⁸*New Zealand Herald*, March 13, Section One, Page 3.

The concept of 'race' therefore remains prominent in New Zealand society, although its use is ideological rather than scientific. It remains socially significant, because common-sense understandings of 'race' are used to explain the behaviour of others and thereby structure inter-group relations (Anderson 1988, 1991; Jackson 1987, 1989; Spoonley 1994; Wetherall and Potter 1992). As a result, Maori (and other minority groups) continue to face personal and institutionalised racism in many forms. Because of, or despite this, Maori have reasserted their cultural identity and traditions and have confronted those institutions and attitudes which are identified as racist (Spoonley 1994: 171). They have accomplished this largely through reaffirming their ethnicity. Whereas 'race' has negative connotations, ethnicity has positive ones and is currently the preferred term for defining difference (Eriksen 1993; Solomos and Back 1996; Spoonley 1988: 40). The term was first used as an alternative to 'race' in the late 1960s, particularly in the US when Black Americans started a resurgence of cultural identity (Orange 1987: 244; Pahiri 1996; Spoonley 1990: 85). The movement soon gained popularity amongst other cultural or ethnic groups such as the Irish, Polish and Italians (Spoonley 1990: 85). Ethnic groups are characterised by particular cultural traditions and history, rather than by physical difference (Eriksen 1993; Spoonley 1994: 173;). It is more about identity and belonging than skin colour and reflects the cultural experiences and feelings of a particular group. Ethnicity has a political nature because in the form of cultural identity, it has been used in political struggles (Dickason 1992 Ch. 27; Dyck 1991: 145-146; Eriksen 1993; Tennant 1990). As Spoonley (1991: 156) argues, 'ethnicity exists when there are political or economic reasons for it to do so'. It is not a static phenomenon, but changes according to specific circumstances (Spoonley 1988: 40-42).

In New Zealand, there are a number of different ethnic groups, that is, groups who share a common ancestry and culture (Mulgan 1994: 23), and a consciousness of cultural identity (Spoonley 1990: 85). The most obvious of these are Pakeha and Maori. Because ethnicity is often seen as pertinent only to minority groups, the idea of a Pakeha ethnicity has, until recently, been ignored (although see, for example, Bell 1996; Berg and Kearns 1996; Jackson 1998). Pakeha, as the dominant group in New Zealand, have not needed to define themselves in terms of their ethnicity. However, the resurgence of Maoridom in the 1970s and 1980s has compelled Pakeha to examine their own ethnic identity. The notion of a Pakeha ethnicity is a politicised one that has become important for a country that has a policy of biculturalism. I say politicised because the use of the term Pakeha has definite liberal or radical political connotations (Spoonley 1991; 1988). Among the more conservative elements of New Zealand society, reaction to the term ranges from indifference and confusion to one of complete hostility. Use of the label Pakeha arises from a political commitment which has evolved from the debates about biculturalism. In my experience, Pakeha can have different connotations. Firstly, as a broad label, it can refer to any New Zealander of European extraction, of any political persuasion. Secondly, it can also refer to a specific group of people of European extraction, who call themselves Pakeha and who are sympathetic towards the notion of a bicultural New Zealand. These people are committed to Pakeha sharing power with Maori. Thus the word and its implications should be interpreted with caution.

Pakeha is a highly contested term, both in popular and academic debate. For example, in June 1996, *The New Zealand Herald* reported there were many

people unhappy with the term, particularly with its use in a Race Relations Office advertising campaign⁹. The article argued that the word Pakeha was the most appropriate for naming and describing New Zealanders of European descent, whose values and behaviours reflected their New Zealand origin, rather than their European ancestry. This sparked off various rejoinders, two of which were printed in the Letters Section the following week. One letter described using the term Pakeha as ‘parochial and unintelligible to the outside world...considered inappropriate by a great many.’ Another referred to the ‘cringe article sponsoring the pathetic term “Pakeha” instead of the now internationally used term “white” to those of European extraction...[and that the article]...used...new age writer[s]...to support out-of-date terminology’. The letter continued by asking whether the author of the article ‘purposely wish[es] to offend much of [the New Zealand] population to appear politically correct’.

Lack of consensus on what it means to be Pakeha is unsurprising because there is no single, unified Pakeha consciousness at present. It is therefore an emergent identity. Although Spoonley argues that Pakeha ethnicity is not under threat (1991: 167) I believe that many people of European origins in New Zealand think it is. But it is not Pakeha ethnicity *per se* that’s under threat, but wider social relations, particularly those of power. Although rarely formulated in these terms, I believe this to be the main reason for the anger and confusion that the term creates. My own position poses other questions. The literature suggests that people who call themselves Pakeha do so from a

⁹“‘Pakeha’ the best word to describe most of us”, *New Zealand Herald*, June 27, 1996, Section One, Page 6.

particular New Zealand perspective (Bonnett 1997: 198; Spoonley 1991: 159). Amongst other things this includes a liberal or radical stance and a unique standpoint gained only from being New Zealand born. Although I have similar political views, I do not possess a New Zealand heritage, and at the outset, I was uncertain whether or not I would be considered Pakeha. This was important because it had ramifications for the ways I might be perceived and treated during my time in New Zealand. To be considered Pakeha would either label me as 'white' or place me in a position with certain political views and sympathies which supported biculturalism and the realignment of current power relations. To be seen as British or English risked being seen as perpetuating the legacies of colonialism, by coming to do research on 'exotic' people rather than with them. In the event, I tended to be seen as Pakeha in both meanings of the word, but one who was ignorant of New Zealand affairs. This was a good compromise and was actually quite advantageous for me because I could ask questions that an 'authentic' Pakeha should already know. This was important for the actual fieldwork. In the words of one Hokianga person, 'You won't upset people because they know you know no better. Ask what you like'. In fact, great tolerance was shown and I'm sure I asked questions that were offensive. I 'got away' with asking these things precisely because I was not a 'real' Pakeha.

In contrast to Pakeha identity, Maori are often portrayed as having a more coherent ethnicity than Pakeha. This is true in so much as they are a minority group disadvantaged by current power relations in New Zealand society. Being Maori is more than a conceptual or classificatory issue, it also has social, political and constitutional ramifications. This is certainly the case today, when Maori grievances are being at least partially addressed (Pool 1991: 11).

For Maori, the fundamental components of ethnicity (and a politics of ethnicity) are land rights, language and cultural traditions (Ramsden 1994; Spoonley 1994: 183). But like Pakeha, Maori are a diverse group of people. For example, some *iwi* fared better than others when the colonisers confiscated land. This has had direct effects on present day situations for different tribal groups, who interpret their fortunes (and their ethnicities) in numerous ways. Disparate circumstances and interests in different parts of the country thus make it difficult to speak of a coherent Maori ethnicity. But these differences tend to be overlooked when looking at health issues, because as a group, Maori have had similar experiences wherever they're from and whatever their histories. Moreover, many of the health problems they face are similar, regardless of where they are from.

The Treaty of Waitangi.

Maori are among the many indigenous peoples of the world who have arrived at their minority status by way of a Treaty of cession with a colonial power (A. Durie 1994: 103). The Treaty articulates the nature of the relationship between the founding peoples of New Zealand by first naming them and then describing their rights and obligations to each other (Southwick 1994: 8). The Treaty of Waitangi is important for Pakeha as well as Maori because it is about partnership between peoples of New Zealand. Any Treaty concern is therefore a matter for both Maori and Pakeha, though this is not always obvious or recognised. The Treaty is often seen as a solely Maori affair, although I would dispute this, arguing that it affects everyone in New Zealand, regardless of their background or ethnicity. It is an important part of every day life in New Zealand and is being acknowledged here because of this. But my reflections on the

Treaty have emphasised the Maori position because they are the people who need most to use it to their advantage. In my opinion, until recently, most Pakeha have not been interested in the Treaty, because they did not need to be. However, Maori reassertion of their ethnic identity has forced people to be less complacent about the Treaty of Waitangi and adjust to treating it as a key mechanism for change within contemporary New Zealand society.

From its inception, the Treaty of Waitangi was a contentious document, which has never been ratified in any legislation. Often regarded as the founding document of New Zealand, it was signed by Governor Hobson and selected Maori chiefs in February 1840 (Owens 1992; Walker 1992; Wetherall and Potter 1992; Williams 1989). Although treaties with indigenous peoples were not unusual in the history of British imperial expansion (Williams 1989), most were shelved or forgotten. This was also true of the Treaty of Waitangi (Orange 1987: 1). Since the 1970s, however, influenced by the civil rights and indigenous peoples' movements from the United States, the Treaty has re-emerged as a prominent and contested issue in present day New Zealand (Kawharu 1989; Kelsey 1991; Spoonley 1988, 1994; Sharp 1991). Even now, there is no clear agreement on the position of the Treaty in the life of the nation.

The Treaty is a brief document that follows precedents set in similar treaties elsewhere such as Canada and the United States (Mulgan 1989, Williams 1989). It acknowledges specific obligations and Maori rights and is an unusual deed because it was written in both Maori and English. However, the meaning of the Treaty differs significantly between the two versions (Brookfield 1989; Fleras 1991; Kawharu 1989: 316-318; Mulgan 1994: 58; Orange 1987;

Owens 1992). Translations of the Maori text show that power was predominantly in Maori hands rather than English. The English text suggested the opposite. At odds with each other, the two versions of the Treaty contained the seeds of enduring conflict, especially over land, power and authority (Orange 1987: 1). There have always been variations in understandings of the Treaty, not only between Maori and Pakeha, but also between Maori and Maori and Pakeha and Pakeha (A. Durie 1994: 114; Orange 1987: 5). As a result, Treaty discourse persists as a discourse that struggles over meanings, interpretations and contested language.

The text of the Treaty was drafted by the British¹⁰ and therefore states their case. It was hastily translated into Maori the night before the Treaty was signed (Owens 1992: 51). In both languages, it contains three apparently simple clauses or articles (Mulgan 1994; Walker 1996: 259)¹¹. In the English version under the first article, the chiefs agreed to cede sovereignty of the country to the Crown (in the person of Queen Victoria). In return, the second article guaranteed

¹⁰Following orders from the British Colonial Office, Hobson and his staff drew up the Treaty with some help from the British Resident, James Busby. It was hastily translated into Maori by Henry and Edward Williams of the Church Missionary Society. The following day, the Treaty was signed.

¹¹There was a fourth, spoken article agreed the day before the Treaty was signed, although this did not appear in the final, written version. It was the acceptance of religious freedom, innovative at the time, because in Britain, religious freedom did not exist. Roman Catholics for example, were not eligible to vote and were allowed fewer property rights. In reality, Maori faced similar restrictions too. The right to vote in the 1850s was based on an individual property qualification of £50 if the land was freehold, or £10 if it was leasehold in town or £5 in the country. Most Maori land at this time was in customary tribal title, therefore most Maori were not eligible to vote (Walker 1990: 111, 143).

‘full exclusive and undisturbed possession of their lands and estates, forests, fisheries, and other properties’. At the same time, it gave the Crown the sole right to buy land from Maori. The third article gave Maori rights and privileges of British subjects (Mulgan 1994: 60; Southwick 1994: 10-12). In the first article of the Maori version, sovereignty was translated as *kawanatanga* (governorship). *Kawanatanga* is a neologism derived from a transliteration of Governor to *Kawana*, which with the suffix *tanga*, becomes ‘governance’ (Walker 1996: 256). Whereas sovereignty implied complete and ultimate power, *kawanatanga* was a word made up by missionaries, which had a vague and doubtful meaning (Mulgan 1994: 60). This clause legitimated the presence of European immigrants in New Zealand, including Governor Hobson, his successors, and eventually constitutional government in the form of Parliament (Walker 1996: 256).

The second clause guaranteed to the chiefs *tino rangatiratanga*, absolute chieftainship, over their lands, homes and treasured possessions. For the chiefs this meant that the British Crown assured them of their own sovereignty, in return for the British to govern (Walker 1996: 258). Governance was seen by Maori as an administrative role rather than as direct rule. But the drafters of the Treaty and the missionaries interpreted the first clause as a clear surrender of Maori sovereignty. The contradiction in this important clause between the Maori and the English versions of the Treaty is at the centre of present day Treaty debate between Maori and Pakeha (Walker 1996: 259).

The third article of the Treaty is less problematic than the first, where meaning was masked by ambiguous translation. This clause was translated

accurately as a guarantee to the chiefs and their people, of all the rights and privileges of British subjects. It constituted New Zealand's first Bill of Rights, including economic and cultural rights, as well as the political rights of democratic values, for example freedom, equality and justice (Walker 1996: 259). But whether Maori actually enjoyed those rights is debatable; and as long as they remain disadvantaged by official policies and practices, they are still not in full receipt of their individual civil rights (A. Durie 1994: 115).

The Treaty has failed to protect Maori interests, largely because historically, the State, has disregarded it and there have been many cases where land and other resources have been taken illegally. Walker (1996: 262) has argued that it is not necessarily the Treaty that's at fault, but that the 'state had subverted the Treaty by its own actions'. There have been major attempts to dispel it, to negate its significance, and to conclude it a simple nullity (A. Durie 1994: 116). Moreover, the State has rejected or ignored the principles of partnership contained within the Treaty. The principles of partnership are an important part of the Treaty, but Maori input into public policies, for example, have not been given a high priority (Rolleston (1989: 44). Durie (1986) states that, 'much Maori discontent today relates to the failure of most Westernised institutions in New Zealand to acknowledge th[e] principle[s]'. Rolleston concludes that 'if the principles of the Treaty of Waitangi are honoured, Maori health, Maori culture, and New Zealand society in general, can progress in a way never achieved before' (1989: 45).

Since the 1970s, the Treaty has become one of the most important, if controversial documents in the life of the nation. In 1975 the Treaty of Waitangi

Act established the Waitangi Tribunal, which interprets the Treaty in a contemporary context. Giving equal weight to both the English and Maori versions¹², the Tribunal dealt only with claims (mostly land) that had arisen since its inception. Legislation in 1985 extended the Tribunal's powers to investigate disputes dating from when the Treaty was signed. With the introduction of retrospective claims, education, policies of adoption, language and social affairs are now coming before the Tribunal. These issues are covered by the Treaty because they are *taonga* - treasured possessions as described in Article 2 and rights as specified by Article 3.

Since free trade and the General Agreement on Tariffs and Trade (GATT), the Treaty has increasingly become seen as an obstacle, particularly by the (National) government of 1991-1996¹³ (Smith 1996). In 1994 the fiscal envelope was introduced. This was a treasury designed policy that set aside one billion New Zealand dollars to resolve Treaty claims, which were perceived as escalating out of hand. There are approximately 500 claims still to be settled and all are meant to be paid for out of the fiscal envelope (Smith 1996). The terms of negotiation in the claims settling process are fixed, and once and for all settlements are the manner in which the claims are solved. The Sealords deal has

¹²Where two contradictory versions of a Treaty exist in two different languages, legal tradition supports a bias against those who offered the Treaty. This is known as the *contra proferentum* convention. In 1987, a Court of Appeal ruling over-rode this principle, giving equal weight to both the Maori and the English versions of the Treaty. The key ruling was that the Treaty was about partnership. Today, the principles of the Treaty, rather than the actual wording are recognised by the Crown. (Treaty of Waitangi Study Day, Rawene, July 17, 1996.)

¹³Since my return, a new coalition government has been elected, consisting of the National and New Zealand First Parties.

taken \$150m already (Smith 1996) and other claims will also take large shares¹⁴. Consequently, there is concern that the fiscal envelope will run dry before other claims are settled. Although there is abundant criticism of the claims process and the way in which they are settled, at the time of writing, there are no other procedures available. At present there is considerable unease because Treaty claims do not deal with political rights (or at best, only deals with them indirectly). Instead they concentrate on resources, especially land, forests and the sea. The fiscal envelope policy is designed to settle all Treaty claims, permanently, by the year 2000. If this policy is successful, then free trade access can happen more quickly - APEC are aiming for all trade barriers down by 2010. The Treaty is therefore tied to wider social, economic and political global processes, as well as ones closer to home.

Since the links between health, power, economic prosperity, control and autonomy have been uncovered, the Treaty has emerged as one of the contemporary cornerstones for Maori health (Durie 1989, 1996; Rolleston 1989; Southwick 1994). Pomare et al (1995: 14) point out that 'until the grievances arising from failure to honour the Treaty of Waitangi are resolved, Maori

¹⁴The Sealords Deal was an agreement signed by 4 Maori representatives (representing 55 iwi) and the Crown in September 1992. It was a commercial settlement of Maori fishing claims which would stop future lawsuits by Maori in respect of commercial fishing claims based on the Treaty of Waitangi (Smith 1996; Durie 1994: 212). Other large claims are the Tainui claim which was settled in 1995 for \$NZ170m, and the Taranaki claim, still to be settled. (The *New Zealand Herald* reported that The Waitangi Tribunal has estimated that several billion dollars compensation would be needed for this claim to be settled, although given that the fiscal envelope is only \$NZ 1 billion, they are unlikely to receive anywhere near this amount. *New Zealand Herald*, Section One, Page 1, June 15, 1996).

ill-health will remain a problem'. Although not immediately apparent, the Treaty contains principles that have important implications for (particularly Maori, but also Pakeha) health. The loss of natural resources such as land, forests and fishing rights has directly affected incomes, socio-economic status and standards of living. These broad social conditions are known to be influential in determining the health status of individuals and groups. An increasing awareness of Treaty obligations, and the retrospective extension of the Waitangi Tribunal's powers are seen by Maori leaders (and some Pakeha) as an important step that may strengthen land as an institution of health (Durie 1986). Health itself has also been described as a resource (Epp 1986; Lee 1982; White 1981), but one that has become largely lost since the separation of people from their land, language, family and cultural environment (Pomare and de Boer 1988). It is harder to quantify and measure the effects of 'cultural' separation than the 'physical' indicators of socio-economic status, nevertheless, they are an important part of the health equation.

Health matters are tied up with ideas of control and empowerment and from this perspective, the first two articles of the Treaty are important because they relate to self-determination. Yet traditionally, Maori have had little if any control over the policies and practices that affect their everyday lives. One result of this is continuing discrepancies in social and economic indicators between Maori and Pakeha. These discrepancies result from breaches of the Treaty (A. Durie 1994: 113), particularly of *tino rangatiratanga*, which is about absolute Maori chieftainship, and hence control, over their own lives. *Tino rangatiratanga* is also about guardianship of *taonga* or treasures. Increasingly, along with other social issues such as education, and adoption policies, health is

being cited as *taonga* - a treasure that historically has been affected and controlled by Pakeha (Armitage 1995; Tuohy 1994: 29). There are increasing calls for Maori to take control of Maori concerns, such as health and education, in an attempt to redress this state of affairs and to some extent this has been successful.

The Treaty's third article guaranteed to Maori all the rights and privileges of British subjects. Health has been described as a fundamental human right although an often neglected one (Lee 1982). Maori lifestyles and health beliefs were dismissed by Pakeha early on. Also, Pakeha-dominated health services submerged Maori values which further contributed to the devaluation of Maori approaches to health (Tuohy 1994). Pomare has argued that equitable access to services is also a fundamental right guaranteed by Article 3 (1995: 144). Yet for many, this right remains unfulfilled. Barriers include ineffective communication strategies for Maori, unresponsive services and staff that don't meet Maori needs, distance and lack of transport, and lack of integrated services (Shipley 1995).

The Treaty of Waitangi recognises the status of Maori as *tangata whenua* (native or indigenous persons, literally 'people of the land'). It is key to Maori empowerment and development because it acknowledges the ideas of partnership, participation and *tino rangatiratanga* (self-determination, absolute chieftainship) (Rolleston 1989: 44). It is becoming increasingly acknowledged by many national and regional policy documents as the starting point for a partnership between Maori and Pakeha. It constitutes an important framework for considering health, especially in regard to the relationship between Maori

and the Crown as Treaty partners. It calls for the Crown and its agencies (including present day health agencies) to be ‘...pro-active in protecting and preserving the unique characteristics of Maori people and their culture’ (North Health 1995).

At face value, there is enthusiasm and optimism surrounding the discourse and rhetoric of the Treaty. Official policy documents contain sections about Treaty obligations and partnerships. But this outward appearance is easily undermined, and some have argued that governments have not accepted that the Treaty is relevant to social policy areas, including health (Durie 1995; Milne 1996). For example, in 1995, the Health and Disability Commission produced two leaflets. One was entitled ‘Code of Health and Disability Services Consumer’s Rights’, the other, ‘Your Rights When Receiving a Health or Disability Service’. As the titles suggest, these documents outlined the entitlements of people receiving health and disability services. Although both documents contain clauses about cultural needs and preferences and discrimination free practices, neither explicitly acknowledges the Treaty of Waitangi. Apparently, the draft versions contained references to the Treaty, but the final version had those references removed (Milne 1996). The Code of Health and Disability Services Consumers’ Rights has been changed to decrease emphasis on the special needs of Maori (Durie 1996). This demonstrates precisely how powerful the Treaty is - or could be (Milne 1996).

3.4: HEALTH AND ETHNICITY IN NEW ZEALAND.

What constructions of health exist in New Zealand? Are they ethnically differentiated? What are their implications for research, practice and policy in the health field? Examining these questions introduces some of the specific intersections of ethnicity and health in New Zealand and sets out the background for this project. The idea that health and illness are socially constructed as well as clinically defined is now well established in the literature (Atkinson 1995; Bair and Cayleff 1993; Dubos 1979; Hart 1985; Jones and Moon 1987; Lupton 1994; Radley 1993; Townsend and Davidson 1992) and confirmed by the fact that different peoples the world over conceive of and deal with health in diverse ways. In New Zealand, as elsewhere, differing concepts of health and health care vary across ethnic, social and professional groups (Spicer et al 1994: 191), demonstrating that health and health care are not objectively defined but closely related to social cultural and political divisions within society. Thus one finds in New Zealand competing conceptualisations of health. The dominant one at present is the biomedical model, which I outlined in Chapter 1. But it has been heavily criticised for its inability to deal with chronic disorders (Hart 1995; Jones and Moon 1987; Lupton 1994; Radley 1993; Saggars and Gray 1991: Chs.4 and 7) which form the bulk of health problems today in New Zealand (Spicer et al 1994). One effect of this critique has been to re-evaluate the biomedical model, broadening its perspective to include socio-economic and cultural variables. (see for example CIAR 1991; Evans and Stoddart 1990; Lupton 1994 Ch. 1; White 1981). Moreover, this viewpoint is becoming widely accepted at the international level, as evidenced by the Alma Ata Declaration and the Ottawa Charter. Ironically, these contemporary broad-based models

resemble many non-western ways of theorising health that have been established for centuries.

Maori conceptions of health have always been based on a broad perspective (M. Durie 1985, 1994; Mackay 1985; Murchie 1984; Pomare 1995; Rankin 1986). This view sees mind-body dualism (which has so influenced modern 'western' medicine,) as unduly narrow, and that other factors are important when trying to understand to make sense of ill-health. One Maori viewpoint is *Te Wheke* (the octopus), which recognises eight 'tentacles' which collectively contribute to well-being (Pere 1991). The first of these tentacles is *te taha wairua* or *wairuatanga*, the spiritual dimension of a person, denoting two waters positive and negative: "Water can give or take life" (Tuohy 1994: 28). It is a matter of keeping balance (Pere 1991: 16). This dimension is generally felt by Maori to be the most essential requirement for health (M. Durie 1994: 71), because it is the life force that determines who they are, what they are, where they come from, and where they are going (Hiemstra 1994: 57). It is not simply or solely a belief in God, rather it encompasses an understanding of the links between the human situation and the environment - particularly in terms of land. The spiritual realm is immersed and integrated with the physical realm. A committed belief in spirituality affects the way in one interacts with people, and relates to his/her environment. This kind of 'collective feeling' is as important today as it was before the arrival of Europeans. Land, or rather tribal land ownership (*mana whenua*) is essential for well-being, and access to tribal lands is therefore mandatory for good health. This is because land has the capacity to produce for the market and/or for subsistence purposes as well as being the 'anchor stone' that provides personal and tribal identity and cohesion.

The second tentacle is *te taha hinengaro*. *Hine* (female) is the conscious whole of the mind and *ngaro* is the hidden, unconscious. *Hinengaro* is the mental aspect of a person, the psychic side of health, and is concerned with the mind, including the intuitive and “feeling” seat of the emotions (M. Durie 1994: 71-72; Tuohy 1994: 32). Thoughts and feelings have the same source in a person and the way these are expressed are vital to a person’s health. Along with the body and soul, thoughts and feelings determine how people feel about themselves, and this affects their health (Hiemstra 1994: 57). The expression of thoughts and feelings often differs between Maori and Pakeha (M. Durie 1994: 71-72). Maori thinking tends to be holistic and integrative rather than analytical, which western modes of thinking tend to be (Durie 1985: 484). Durie continues that “...a culturally different communication style may place Maori children, and adults, at a disadvantage when the cognitive, analytical mode of thinking prevails, while from a health viewpoint, frustrated self-expression is likely to lower morale and reduce wellness” (ibid.). This, and the lack of ‘safe’ environments in which to express those thoughts and feelings, means Maori people are exposed to increased levels of stress. It therefore makes sense to include thoughts and feelings as integral components of Maori (and other) conceptions of health and well-being.

The third tentacle, *te taha tinana*, embodies the physical aspects of health, including personal autonomy. This is the province of the more familiar ground of western medical models, where the body and physical health are the subject. From a Maori viewpoint, *taha tinana* is about the sanctity of each person, coupled with the idea that everybody requires a set of disciplines to ensure the sacred nurturing continues. Each person needs to find an appropriate

health package that can cater for their individual needs. The disciplines include recreation and physical exercises, cultural practices, knowledge of Maori foodstuffs and herbal medicines. Each person is a universe and needs to have dominion over themselves (Pere 1991: 24). In addition, certain cultural practices are important to Maori for health reasons. For example, there are established conventions surrounding bodily functions such as washing or eating food. These practices are polar opposites and must therefore be kept apart. People do not wash their bodies at a sink that is used for food preparation. As Sarah¹⁵ once remarked:

“I can remember one old guy...if you washed - say your knickers - you washed in the sink. This old guy would say to you, ‘You don’t peel potatoes and then go and wash them down the toilet, before you put them on’”.

The fourth tentacle is *te taha whanaungatanga*, or the extended family. Whanaungatanga is based on ancestral, historical, traditional and spiritual ties. It forms the bond that influences the way people live and interact with their families, society, and “the world, the universe” (Pere 1991: 26). Pere argues that this is the area that poses considerable challenges for people who live in and out of different ideologies. As an example, she cites the Maori people and the Treaty of Waitangi. The English partner represented the Crown, a symbol that stood for the divine right of Kings, while the Maori partner[s] stood for the “divine right of everything across the universe” (ibid.). This created problems because it was difficult for Maori to reconcile these two differing ideologies. To a large extent,

¹⁵Sarah was my ‘key informant’ for the evaluation study. She is a Maori *whaea*, which translates as a community ‘auntie’, a highly respected figure.

this remains the case today. It is in this context that the immediate and wider family have many implications for health. The importance of the extended family's role in contributing towards good health and support is appreciated by Maori. Physical health cannot be detached from other aspects of health, and people who are unwell cannot be cared for in isolation from their families (M. Durie 1994: 73-4; Hiemstra 1994: 57). As well as forming a general support network, the extended family has traditionally been involved in specific practices, such as child rearing, acknowledging the role and experience elders have in the nurturing of children. Elder's health is also often looked after by the wider families, as a mark of respect for their special status as an elderly person. Murchie (1984) argues that *te whanau* transcends the life of its members, that it is at once "...a link with the past through revered common ancestors and a foundation for the future through its responsibility for the nurture of the young".

The fifth tentacle comprises *whatumanawa* or emotional aspects. This is the open and healthy expression of emotion that is necessary for healthy human development (M. Durie 1994: 75). Every emotion has a time and a place for expression, and Pere argues that we all should be encouraged to express, rather than suppress our emotions. She goes on to remind us that every emotion has a positive and a negative side to it. These examples are presented overleaf.

RANGA WHATUMANAWA. (Relating to the emotions and senses)

(Source: Pere 1991: 30)

POSITIVE

unconditional love

hate of cruelty to children

anger at the effect of negative

jealous of a person's skills to
the point where you improve your own

sadness over a family bereavement

being proud of your cultural identity

joy for the spirit of freedom

NEGATIVE

possessive love

hate of children

anger at the person
who made the
negative statements

jealous of a partner
who receives
positive comments

sadness at missing
out on a gambling
engagement

being too proud to
apologise for hurting
someone

joy at the cost of
someone else's
freedom

The sixth tentacle is *mauri*, or the life 'force' in people and objects including language (the Maori for language is *te reo*). *Mauri* is an abstract concept and very difficult to define in English, but broadly speaking, it refers to a person's life principle and psyche (Pere 1991: 12). All things (both animate and inanimate) have a *mauri* that exists as long as they do. This *mauri* must be appreciated and respected, because it helps people relate and care for everyone and everything across the universe. *Te reo* encompasses language modes and communication. It enshrines the ethos, the life principle of a people and gives sustenance to the heart, mind, spirit, and psyche. It is paramount (p. 10). *Te reo* is the life line and sustenance of a culture, it provides the tentacles that enable a child (I would argue also adults) to link up with everything in their world (p. 9). *Te reo* is one of the most important forms of empowerment that a child or adult can have. It is important not only as a form of communication, but also as the main way in which the values and beliefs of a people are transmitted (ibid.). This is important for the thesis in two ways. Firstly, Pere is acknowledging the role that language (and therefore narrative and discourse) plays in shaping our ideas, beliefs and practices in the everyday world (see also Chapters 2, 6 and 7). Secondly, that because language is key in passing on values and traditions, it is critical when it comes to notions of culture, embodiment and difference (see Chapters 2 and 7). As well as spoken language, non-verbal modes of communication are important, and included in the definition of *te reo*. Sign and body language has messages for people to read. Facial gestures, eye, head, hand, arm and leg movements reveal a great deal regardless of whether one is speaking or not. Pere points out that developing this type of observational skill will help children (and adults) read the signs and changes in the natural (and, I would argue, the social) environment (p. 9).

The seventh tentacle is *mana ake*, the positive identity based on the unique characteristics of an individual and their family. The meaning of *mana* is “multi-form and includes psychic influence, control, prestige, power, vested and acquired authority and influence, being influential or binding over others, and that quality of the person that others know she or he has” (Pere 1991: 14; see also footnote 4, this chapter). The last tentacle is *ha a koro ma a kui ma*, the breath of life that comes from one’s predecessors. These are the inherited strengths and the affirmation that good health is linked to an appreciation of ancestors and their role in forging the family.

Another common approach is *Te Whare Tapa Wha*, which is a simplified version of *Te Wheke*. It recognises four cornerstones of health that act together like the walls of a house (M. Durie 1994). If one of the walls falls down, the others will fall also. Each side is essential to the maintenance of the other walls. Various authors have identified the four cornerstones as: *Te taha wairua* (a spiritual dimension); *te taha hinengaro* (a psychic dimension); *te taha tinana* (a bodily dimension); and *te taha whanau* (a family dimension) (M. Durie 1985, 1994; Mackay 1985; Murchie 1984; Pomare et al 1995).

Te Wheke - the Octopus.



Te Wheke - The octopus.

The head represents the child and the family. Each tentacle represents a dimension that requires and needs certain things to help give sustenance to the whole. The suckers represent the many facets that exist within each dimension. The tentacles move in and out in an infinite direction for sustenance when the octopus moves laterally. The tentacles can also be intertwined so that there is a merge, with no clear cut boundaries. The dimensions need to be understood in relation to each other, and within the context of the whole (Pere 1991: 3).

From a Maori perspective, health is a positive and comprehensive concept (Madjar 1992: 125) that is integrative rather than fragmented (Durie 1984). It combines a spiritual awareness with one's ancestors and environment, as well as the self. Tribal and familial affiliations (including the extended family and ancestral land) give a sense of belonging that is known to be important to health. Positive links between health and ethnicity are fostered through affirming cultural identity (Durie 1996). Cultural identity is more than a sophistication of mind, its also to do with accessing cultural institutions such as knowledge, language, land and history. Ethnicity is part of cultural identity (Eriksen 1993: 11; Hiebert 1994: 173-174; Spoonley 1988), and cultural identity makes a difference to health (Aggleton 1990: 26; Durie 1996). A research project at Massey University (entitled *Te Hoe Nuku Roa*) is currently examining cultural identity profiles and looking for linkages between cultural identity, socio-economic status and why changes occur. The trends of preliminary results show that over half of those with a sound health profile also have a secure cultural identity. Two thirds of those who receive state benefits also have a threatened health status profile. The implications of these preliminary results suggest that there needs to be a dual approach to health issues through both economic restoration and cultural security (Durie 1996). The current Maori position is largely a result of cultural and land alienation. In this context, the Treaty of Waitangi is important because economic restoration and cultural security are inextricably linked with land and social issues. Other cultural institutions - *marae*, *whanau*, *hapu*, *iwi*, are also crucial to Maori identity. But without the bond with land, it is difficult to access other cultural institutions and this has been the experience for many Maori (Durie 1996; Walker 1990).

It is clear that any study of health must acknowledge its embeddedness in the social milieu. For New Zealand, this includes two very specific social relations that are intimately related to each other. They are not only important for understanding the general New Zealand context; they are also crucial in understanding current health practice and policy in New Zealand. The first of these is the notion of biculturalism; the second is 'cultural safety'. Settler societies the world over perceive their own cultural and ethnic relations in different ways. The United States for example, has long advocated a 'melting pot' style, where immigrants and indigenous peoples alike are expected to assimilate into (white, middle class) American life, and do things 'the American way'. Canada in more recent times has adopted the phrase 'cultural mosaic' to describe a situation where different cultures and peoples (theoretically at least) live harmoniously side by side, all contributing to the enrichment of everyday life. New Zealand's approach to dealing with Maori and Pakeha relations can be divided into three main periods; one of assimilation from roughly 1847-1960; one of integration from 1960 onwards and a period of Maori resurgence and biculturalism since 1975 (Armitage 1995; Orange 1977 quoted in Pearson 1991: 206; Spoonley 1988: 77). At present, biculturalism figures large on the social and political agenda. Although there are many peoples with diverse ethnic and cultural backgrounds in New Zealand, an official policy of biculturalism has been adopted because it was Maori and Pakeha who signed the Treaty of Waitangi, the original founding document of New Zealand. Biculturalism thus gives prominence to two cultures and traditions, the dominant Pakeha one and the Maori one. It also stresses the unique position of Maori as the country's first inhabitants and signatories to the Treaty (Mulgan 1994: 34).

The cultural nationalism advocated in New Zealand in the 1980s gave way to a bicultural post-colonial form in the 1990s. Loosening ties with Britain allowed New Zealanders to reflect on their own changing position, from that of a former colony, to a country with its own internal economy of colonisation. Biculturalism, as an affirmation of partnership principles of the Treaty, was one result of this change. Biculturalism has been defined as 'a form of decentralisation which sees control transferred from a centralised Pakeha-dominated State.'(Spoonley 1988: 103). There are other definitions, but common to all of them is a commitment to establishing Maori and Pakeha as equals rather than one being dominated by the other. The notion of biculturalism challenges Pakeha to '...explore the possibility of establishing a degree of partnership between Maori and Pakeha,' (Spoonley 1990: 29). A bicultural stance involves a recognition of past injustices to Maori and a willingness to remedy them (Mulgan 1994: 174). In the form of greater decentralisation and increased Maori ethnic autonomy, biculturalism could be one mechanism for the realisation of Maori sovereignty as guaranteed by the Treaty of Waitangi. Taking a bicultural approach is not intended to belittle or silence peoples of different ethnic or cultural origins, but it is seen by some as the starting point for a successful multicultural society. Thus, 'In acknowledging the possibility of a bicultural world view, we can also extrapolate that there are many world views, many ways of knowing, that inform us...biculturalism and multiculturalism are part and parcel of our lived experience. Diversity is something we wish to celebrate, rather than a problem to be overcome...' (Southwick 1994: 7-9).

Spoonley (1994) notes that there is a certain amount of confusion that surrounds the idea of biculturalism, to the extent that it has been seen by some

Pakeha as a threat. The result is that some Pakeha want to side-step issues of biculturalism and implement a form of multiculturalism. This is seen as a soft option by others, because it dissipates resources across many groups and discourages ethnic solidarity (Spoonley 1988: xi). Moreover, multiculturalism does not necessarily acknowledge the unique position of Maori. Biculturalism itself has not been without its opponents in political and social spheres either. It has been argued that making the New Zealand mainstream more bicultural might do little to address the 'needs and interests of those who are so uncomfortable in society's institutions that they will choose to avoid them if at all possible' (M. Durie 1994). In reality, a truly successful bicultural society would be acutely difficult to achieve. For a start, there would have to be more Maori MPs in Parliament (Mulgan 1994: 127). But achieving a bicultural society would also be hampered because biculturalism assumes that both Maori and Pakeha are aware of, and comfortable with their own ethnic identity. This is problematic, particularly for some Pakeha, because as I have outlined above, they are not familiar with their own ethnicity. As long as this state prevails, Pakeha will continue to have difficulties with biculturalism because they are unable to react with others who are asserting their own ethnic interests. Successful biculturalism requires Pakeha to examine their own practices and societal institutions and ultimately transfer a good deal of power to Maori, so that both groups can operate as equals within society. In theory this would produce a system of partnership rather than one of separatism, although if Pakeha refuse to accept this then a degree of separation would be inevitable (Awatere 1984). However, giving up power is something that does not come easy to any group in any society and this reluctance prevents a bicultural society flourishing.

Despite the rhetoric, other minority groups in New Zealand *do* see biculturalism as ignoring their concerns (Pearson 1991; Spoonley 1988: 106). The politics of aboriginality have effectively marginalised the claims of immigrant ethnic minorities, although this has not stopped some critics of Maori claims from using multiculturalism as a shield to deflect bicultural demands (Pearson 1991: 210). Both multiculturalism and biculturalism persistently reify 'culture' at the expense of class and gender divisions to the extent that these divisions are simply overlooked by both majority and minority elites who benefit from sex and class hierarchies within society. Thus biculturalism does nothing to empower the most disadvantaged groups within Pakeha or Maori society. It simply takes ethnicity as its starting and end points, disregarding other, perhaps equally important divisions within those societies.

Facets of biculturalism have clear consequences for health policies and services. From the early eighties, health authorities and health providers began acknowledging the importance of Maori health perspectives. By 1984 the Department of Health was taking a leading role in promoting bicultural approaches to health (M. Durie 1994: 105-106). These included formally acknowledging the Treaty of Waitangi and providing space for Maori to take an active and positive role in Maori health. This meant that health professionals and the State no longer had sole charge of Maori health issues. Cultural safety, as a specific practice of biculturalism has been a crucial part of this process. The principles of cultural safety are by no means limited to the fields of health and health care, but this is where it began. Maori health statistics show that New Zealand's health services, which were primarily ethnocentric and monocultural, have until recently failed to validate Maori health perspectives (Costello 1994;

Tuohy 1994). Treaty rights have been ignored and Maori have not been provided with positive health experiences and/or role models in the health field (Costello 1994). In response to this situation, the principles of cultural safety were developed in the nursing curriculum of the late 1980s and early 1990s. Cultural safety affects not only the content of nursing education, but also the context in which all health professionals and their clients interact (Tuohy 1994: 29). The Maori emphasis in cultural safety is an acknowledgement of their particular status as *tangata whenua* and their particular health experiences, which are in large part the consequence of structural disadvantage. A culturally sensitive attitude to Maori clients is more important for nurses than knowledge of specific Maori protocol and custom. But this attitude is not always inherent in health professionals, and therefore needs to be taught (Tuohy 1994: 27-28). Cultural safety is now a compulsory component of New Zealand's comprehensive nursing programmes. It aims to ensure non-violation of attitudes, values and actions which affect Treaty obligations and the practice of *tino rangatiratanga* (absolute chieftainship over lands, homes and treasured possessions including health) (M. Durie 1994: 116-7). Although the precise terms of a culturally safe approach are still being worked out, it has been defined as an 'attempt to reorient the training of health professionals towards a more critical understanding of colonial structures and their impacts on contemporary Maori', (Dyck and Kearns 1995: 141).

Cultural safety focuses on the experience of the recipient and involves transferring power from providers to consumers (Kearns 1996; 1995). It compels health practitioners (who are overwhelmingly of European extraction,) to examine and understand the impact of their own culture upon the reality of

Maori (M. Durie 1994: 116; Tuohy 1994). This allows an appreciation of how the contemporary circumstances of Maori are rooted in a colonial past, as well as how and why a culture of blaming the victim has become so prevalent in New Zealand¹⁶. Cultural safety insists on analyses of power relations that take account of historical and social contexts so that the critique reaches beyond appearances in clinical and community situations (Kearns 1996). It focuses on two levels, the individual and the collective (ibid.). At an individual level, professional consumer relations are infused with power dynamics, affecting the nature of the encounter between health professional and client. At a collective or societal level, the location and experience of indigenous cultures coincide with structural disadvantages that manifest in (amongst other things) poor health. By centering on these two levels, a culturally safe approach permits health professionals to firstly, examine their own reality and attitudes; secondly, to become open-minded and non-judgemental; and thirdly, not to blame the victims of historical and social processes for their ill-health, social problems and position in society. Cultural heritage continues to shape ideas, attitudes and reactions, particularly at stressful times, such as those of illness (M. Durie 1994). Cultural safety, as an expression of biculturalism, is about providing culturally effective services that take account of particular needs and expectations of different ethnic groups, particularly Maori. It means that people in the health field need to be ‘...fully conversant with the historical and contemporary circumstances of Maori people’ (Dyck and Kearns 1995: 137).

¹⁶Consedine has argued that in New Zealand, blaming the victim is so prevalent, it has achieved the status of a national sport (1989: 178).

Cultural safety has implications for the ways in which we do research. Of course, researchers must be culturally safe as discussed above. In addition, there is a need to reflect carefully and critically on our research and its applications, the ethics of which are often marginalised into committees. As researchers, our words and actions have power in both defining and solving problems in the health field, often to the detriment of the subjects of that research. We also need to understand more fully the position of 'the Other' in teaching and research and that means designing research that is not only theoretically informed, but also where 'we' speak *with* them, not *about* them (Kearns 1996; 1996a). These strategies could produce research that is not only useful to its subjects, but also has allowed those subjects to have actively taken part in defining and shaping the research.

3.5 CONCLUSIONS.

Inequalities in health run along many axes, many of which intersect or coincide. These axes include characteristics such as age, class, gender, disability and region (Legge 1996). Current economic policy reform is widening the gaps within and between axes, so that the health disadvantages of 'class', for example, can be seen as indicators of economic injustice and the health disadvantages of 'race' reflect the continuing effects of colonisation (Curtis and Taket 1996). In this way, health status can be an indicator of wider social problems.

This chapter has sketched out what I believe to be the most important background considerations for this particular project. It was not intended as a

comprehensive or definitive guide to 'the New Zealand situation', but simply to provide a framework of the operating environment within which this project was carried out. Ethnicity and health affect each other in both positive and negative ways and the outcomes are highly context (including place) specific. Health status is to a large extent but one expression of wider social structures, the operations of which often disadvantage and disempower minority groups. The uneven distribution of power and/or access to it is detrimental to the health-status of marginalised groups for example ethnic minorities, elderly and disabled people. New Zealand parallels other industrialised countries' broad experience of health and disease, as well as recent socio-political upheavals, such as economic deregulation, erosion of the welfare state and increasing intercultural sensitivities (Spicer et al 1994: 9). The prevalence of Pakeha institutions, including ways of conceptualising and dealing with health, are a reflection of power relations embedded within New Zealand society. This is now being challenged by the introduction of strategies that draw explicitly on the Treaty of Waitangi, for example biculturalism and cultural safety. The Treaty can be seen as a liberating document, although how liberating it is in the future depends on the balance of power within New Zealand society. Nevertheless, these are the main issues that are currently prominent on the political (including health) agenda and are increasingly becoming a part of everyday life in New Zealand. The next Chapter examines these notions as they are played out in the Hokianga area of New Zealand. In so doing, I also examine my own position in the research, how I negotiated access, and how I ended up doing the actual research I did. These understandings, and my position within them, are important because they are crucial to the ways in which I saw and experienced

the Hokianga, and therefore in large part influenced the end product of my research.

CHAPTER 4. ENTERING THE RESEARCH ARENA: THE HOKIANGA.

4.1. INTRODUCTION.

In Chapter 1, I suggested there were three key dilemmas for current social research; the theoretical and practical gap between academic research and policy makers, the need for contextualised theory, and the thorny question of research politics. In Chapter 2, I reflected upon theoretical concepts, including discourses and some of the real life impacts which notions of otherness have had. In that Chapter, I focused on 'race'/ethnicity and disease as prominent examples of how people were perceived as 'different', although I acknowledged that there were any number of traits that could marginalise groups and 'other' their identities. In Chapter 3, I developed and contextualised these theoretical ideas, by examining both health issues and the actual consequences of being a 'racialised' other in a New Zealand context. Staying with the New Zealand situation, this Chapter revisits and extends the previous chapters. There are two broad sections to it. First, I introduce the locality where I worked: the rural and isolated Hokianga. As a preface to this section, I include some of the current trends within rural geography, both in the UK and New Zealand. Second, I do not want to present a depersonalised Hokianga, but one in which I was thoroughly immersed: thus in this chapter, I also consider the practicalities and politics of research and research relationships, through documenting some of my own experiences of undertaking research in the Hokianga. These reflections on positionality and reflexivity are crucial to understanding me and my research in the Hokianga. Taking note of Bair and Cayleff's warning, that one must not

become so ‘...immersed in ideas of cultural difference that the political and socio-economic origins of illness...are overlooked’ (1993: 89), my aim is to give an account of the Hokianga and my own experiences that pays attention to economic, political and social issues as well as cultural ones. This chapter therefore introduces the setting and circumstances under which this project was carried out. The next Chapter, (Chapter 5) gives a separate critical account of more specific methodological issues.

‘The rural’ is a slippery concept. Although definitions of ‘the rural’ have long been a point for discussion in Britain, (Cloke 1994a; Halfacree 1993; Hoggart 1990), this debate has had little impact in New Zealand, where definitions are still based largely on population size and land-use (CAB 1993; Carter 1990; Kearns 1996; Willis 1988). Here, rural areas are usually defined as those areas which are outside population centres of 1000 or more. A rural village (or township) is a population centre of fewer than 1000, to be found within rural areas. This implies some grouping of houses. A rural district is a geographic location that may focus on a central point but with little grouping of housing at that point. A rural community is an implied network of relationships among the residents of the above (Hatch 1992; Lloyd 1974: 97; Willis 1988). These are standard textbook and census definitions, but as Joseph and Chalmers point out, rurality is a multi-dimensional construct that ‘...defies easy generalisation. Differences in phenomena or process may sometimes be a by-product of whether rurality is conceptualised in ecological or socio-cultural terms...’ (1992: 394). I am not content to take a solely atheoretical approach when thinking through the rural. Instead, as I outlined in Chapter 2, I am also interested in notions of difference, marginalization, identity and power within the rural arena, and how

socio-cultural notions of the rural are constructed. I return to these issues in Chapter 6, where I link constructions with the rural together with health issues.

Notions of rurality in New Zealand differ widely from those in the UK, where research tends to be more theoretically nuanced (see for example the debate in the *Journal of Rural Studies* between Philo (1992a, 1993) and Murdoch and Pratt (1993, 1994)). Moreover, in terms of practice, rural geography in Britain has cast a wider net. There exists a wealth of diverse research, for example, on notions of the rural idyll (Bunce 1994; Mingay 1989; B. Short 1992; J. Short 1991); the commodification of the countryside (Urry 1988, 1990; Shurmer Smith and Hannan 1994: 193-196) and the convergence of cultural and rural geography (Cloke and Milbourne 1992; Cloke et al, 1994; Crouch 1992). In contrast, New Zealand rural geography has conventionally concentrated on farming issues (see for example, Hatch 1992; Kelland 1993; Taylor et al 1987). Given that New Zealand's economy traditionally relies heavily on the agricultural sector, and that farmers are a powerful interest group, this is perhaps understandable. However, like Britain, people living in rural New Zealand are not homogeneous, and not all of them are connected with farming or agriculture. Mainstream rural geography in Britain has been criticised for neglecting 'other' rural geographies, such as those of children (Philo 1992a). This criticism has been tempered by recent publications such as Cloke and Little (1997) and Milbourne (1997). In New Zealand, however, the practice of equating rural geography with agricultural geography continues to mask other rural geographies, rendering all inhabitants as politically, socially and economically the same (Kearns 1996). Rural geographies of children have been ignored, but so too have the geographies of many other groups, such as the

chronically ill, women and Maori, for example. In both countries it is therefore clear that the agricultural sector is in no way synonymous with the rural sector, and that it is time to acknowledge other groups of people in rural spaces in a sensitive manner (Fischer 1980: 23; Mills 1995; Pearson 1990; Pomeroy 1992, 1994; Taylor et al 1987).

Rural parts of New Zealand have changed dramatically since World War 2. This is largely a result of Maori migration from rural to urban places, in search of work and better opportunities for themselves and their families. Pakeha moved into towns as well, but not at the same rate as Maori. For example, in 1926, 84% of Maori were rural; by 1986 this had declined to just 19% (Costello 1994: 22; Pomeroy 1992). These changes mean that New Zealand is now highly urbanised (Allan 1996; Pomeroy 1992: 496 Thorns 1990). But as urban employment opportunities have declined, Maori are increasingly moving back to rural areas, to their *papakāinga* (traditional home base). In addition, non-Maori who have also been unable to find work, or who see the cost of living as cheaper in rural areas, have moved into rural communities.

This in turn has put pressure on rural communities. Northland, for example, has a rapidly growing population and a high unemployment rate (HHET 1994; Pomeroy 1992: 498). In the Hokianga, this increased pressure is felt in many ways. In addition to high unemployment rates, health and education resources are being stretched to the full. From a rural perspective questions that need to be addressed include: What does rurality mean for health and health care? Do we need to address rurality separately to other factors such as socio-economic status or ethnicity for example? Are rural areas sufficiently

different that their needs differ? Many authors see rural areas as no different to urban ones. Pearson, for example, argues that rural populations are no more or less socially homogeneous than urban ones and rural communities in New Zealand reflect the same divisions of class, gender and race as urban communities (1990). Presumably then rural areas warrant no special attention. Yet, given the large-scale return of Maori back to rural areas, and the difficulties of isolation and distance, I am not sure I agree with Pearson. In terms of health care, we must pay attention to the specific rural situation. I believe the answer to these questions is yes, because rural health is a vulnerable area in the health service. Little attention has been paid to their special health needs, or the fragile nature of health care networks in rural areas. These issues are not appreciated by those who have no experience of working in them (Holmes 1992).

Rural health issues include: (i) distance and lack of transport; (ii) withdrawal of amenities; (iii) support services; (iv) choice in carers; (v) and social issues (Holmes 1992). Distance and lack of transport is a major rural health issue, because of its impact on access to services. Withdrawal of amenities is a feature of rural life: over the last fifteen years many services have been lost to rural communities, for example, banks, post offices, schools and pharmacies. Support services in rural areas are few and rely heavily on volunteers, who are ageing at the same rate as the rest as the community. For example, ambulance services, meals on wheels and family support for terminal care could not continue in rural areas without voluntary support. Choices in health carers do not exist in rural areas. The doctor and nurse are people you meet at the store, at church and at the school. If a patient and a health care worker disagree, they tend to be stuck with each other, whereas in the city, the

can go their separate ways. Finally, the interactions of social, economic and health issues are very marked in rural areas. Unemployment is often masked by people doing a bit of (often seasonal) work and therefore underemployment is a real problem for some. At the same time, the health reforms of the 1990s have provided a fast changing backdrop to this situation. These reforms established the purchaser/provider split; attempted to integrate primary and secondary care; integrate funding; define a range of core health services that should be available to everybody, and established separate systems for public and personal health. These reforms have impacted on different areas in different ways. Small-scale studies are therefore necessary if we are to understand the nature of the reforms at a local level.

One reaction to the stress faced by rural areas is the rural health movement. In New Zealand, it is, as yet, relatively young, and there has been little discussion within it, of what rural actually means (Allan 1995: 13). This movement takes its inspiration from international research, (particularly Canada, the US and Australia), where the delivery of equitable and effective health services to rural people has been an issue for some years. From an Australian perspective (but one that might apply equally elsewhere) Sarrantakos (1998) argues that contrary to the notion of the rural idyll, rural communities are experiencing serious social and economic problems mainly associated with distance, isolation, the lack of services available to remote areas, and the effects of natural disasters. This reflects the research evidence of Canada and the US. However, within the New Zealand literature there is disagreement as to whether rural living contributes positively or negatively to health. Authors such as Willis argue that rural areas in New Zealand have always fared well in terms of

education and health facilities and therefore educational and health status. (He could be criticised here for assuming that health equals health care). Many other authors disagree. Holmes (1992) has argued that the past twenty years has witnessed an increasing marginalisation of rural health issues through withdrawal of amenities, support services and choices in health carers. Griffiths (1995: 46) has shown there are clear differences in the health status of rural people compared to those living in towns and cities. He argues that the belief that people in rural areas have better living environments than their urban counterparts is far from reality, given the isolation, lack of facilities, and poor living conditions experienced by some rural people. In addition, he asserts that access to services are inextricably tied up with ethnicity and gender concerns, and that the support needs of older people with age related disabilities is a particular problem in rural areas. Older people are often forced to move to larger centres to get the support they need. Matheson (1995: 68) claims that the move to home based care for a number of conditions assumes the sick person has a home that is dry and warm, has enough space, clean water and inside toilet facilities (1995: 68). This is more likely to be an urban experience than a rural one: urban centres tend to have piped water (not from a tank on the roof) and indoor toilets. From my own experiences in the Hokianga, I know that this is not always the case there. Recorded in my research diary are the following. This type of housing is certainly not uncommon in the Hokianga:

‘Evelyn’s house was built onto a caravan. Firstly, the caravan was there, (it is now the master bedroom) and then they extended out with bits of wood, tin and black plastic sheeting. They got power last year. The floor was covered in old bits of mats and carpets, and some goatskins. The goatskins belonged to them; they ate a couple of goats, fed the rest to the cats, and cured the skins. They have a self-composting toilet which they empty around the base of the feijoa

(trees) at present. They have recently got running water that comes from the tank'¹.

'Ruth's place. She lives in a metal garage. She has a telephone but no power. She has an oven that is powered by gas cylinder. The floor is concrete, no covering. The whole room is about 10 feet by 18. A bed, table, and chairs are the furniture. She used to live in a great big house with her husband, they split up and now she has to live in this metal garage. Her son lives there also, in a room built onto the side. It is 2.4 miles from the nearest store - and no transport'².

Obviously, rural living will have both positive and negative effects on the health status of residents, but the evidence suggests that the effects are closely intertwined with socio-economic status. Those with a marginalised status are often burdened further through lack of transport and access to facilities. These people have little power to voice their opinions and therefore their concerns often go unheard or ignored. In this sense, there are clear links with the theoretical concepts I introduced in Chapter 2, particularly in terms of which discourses come to dominate, and the disempowering features of sickness. To these discursive formations of otherness can be added rurality and socio-economic marginalisation, important features for the thesis because the Hokianga, the area I chose to work in, is generally regarded as both rural and marginalised (HHET 1994; Kearns 1991, 1998). Disabled people in the Hokianga are therefore situated at the intersection of multiple marginalisations - including amongst other things, their rurality, their socio-economic position, and their health status.

¹Diary 2, Entry for 4 May, 1996.

²Diary 2, Entry for 28 May, 1996.

4.2. POSITIONING HOKIANGA.

The Hokianga, in the northern part of the North Island of New Zealand was where the fieldwork for this project took place. Concentrating on one small area made the project manageable. It also resonates well with the literatures upon which I am drawing and which were outlined in Chapter 2. Small scale studies recognise that ‘people make a difference and place makes a difference’ (Gregory 1984: 74), and because of their manageable size, they can capture the ‘flow of human agency as a series of situated events in space and time’ as a contextual account should (Thrift 1983: 1). This section describes the local context within which I lived and worked as well as the rationale and history of undertaking this project. I also return to the dilemmas for social research that I outlined in Chapter 1, that is (i) the gap between academics and policy makers; (ii) the need for contextualised theory to accommodate the particular circumstances of different regions - that place matters and (iii) that the politics of research constantly remind us of the tensions involved in issues of representation and of ‘speaking for others’. Addressing these issues in relation to the Hokianga may go some way to providing a contextualised picture of this place. It also highlights issues which are not simply academic concerns, but which have very real consequences for everyday life wherever research is carried out.

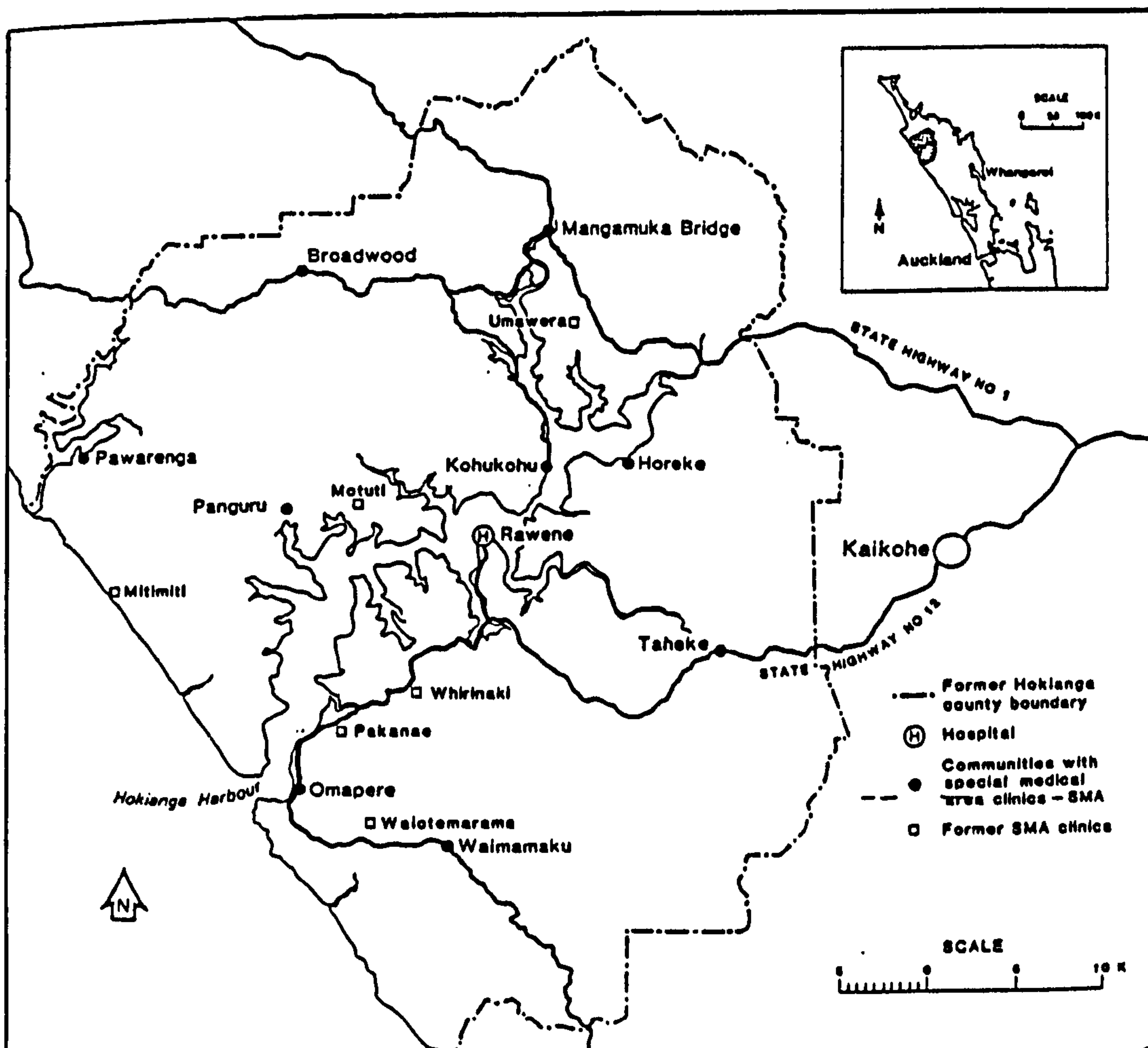
A ward of the Far North District of New Zealand, Hokianga’s rich history means it is an important place at both the national and the local level³.

³It is, perhaps surprising then, that there is a marked lack of literature about the area.

The oldest Maori and the second oldest European settlements in New Zealand were here. Hokianga is sacred to Kupe, the Polynesian navigator who discovered New Zealand around 1000AD (Brownson nd; Kearns 1998). After some years, Kupe left the Hokianga and returned to Hawaiiiki; later generations named the place “*Te Hoki anga nui o Kupe*”, the place of Kupe’s great return. In time, later generations followed, stayed and prospered. European settlement took place largely through the consent of local *iwi* (tribes) and *hapu* (sub-tribes) (HHET 1994).

MAP 3. THE HOKIANGA.

(Source Kearns 1991)



From the 1820s onwards, a steady stream of European migrants moved in and throughout the late nineteenth and early twentieth centuries, the kauri forests and dairy farming provided the major sources of income. However, these favourable conditions did not last long. By the mid-twentieth century, the area was in decline and the population began to drift south (Walker 1994). Economically now the poorest part of Northland (Kearns forthcoming) there is little opportunity for work in the Hokianga. 77% of the active workforce is on unemployment benefit, with others on invalid, sickness and domestic purpose benefits (HHET 1994; *The Northerner*, August/September 1994, pp. 22-23). Most work is casual or unwaged. The only regular, waged work is in the government sector, particularly in schools and healthcare.

This rural and relatively 'remote' area has a low population density, and sometimes people express surprise when seeing the Hokianga for the first time. For example, in April 1996, one of the home helpers, whose husband is the local baptist pastor, invited me on a vintage car rally. My diary entry for Saturday 30 April reads:

"Went on this vintage care rally which was reasonably unremarkable, except for some comments made by the (very nice) couple I was travelling with (in a 1938 Hudson). I was able to write this down all verbatim because I had a sheet/map/clues handout on which to write...[the lady of the couple said] "They've got rules of their own up here...what would you want to build a house up here for?!" On seeing the bus at the bottom of Waiotemarama Gorge... "Goodness gracious!" - and that was without seeing the dogs and the family who live in it. Finally, heading up the Gorge Road, towards the Labyrinth, [she exclaimed] "...[Y]ou would think arriving here that you'd come to the end of the world!" What really surprised me was that these people really had no idea that parts of the Hokianga are like this...."

The largest centre is Opononi/Omapere which has a population of 600 (HHET 1994). Low population density means that many folk live far from main roads, neighbours and support networks. One in seven households have no car and public transport is very limited (Kearns 1996). Since the 1980s, however, the Hokianga has experienced a large-scale return migration, from the cities back to the countryside, to become the second fastest growing part of Northland. The intercensal growth rate from 1976-81 was 6.3%; between 1981-86 this increased to 20.4%, dropping only slightly to 19.4% in 1986-91. The 1991 Census recorded the resident population of the Hokianga as 6,147 (ibid.)⁴. As well as people moving 'back to their roots', young farmers and 'alternative lifestylers' have also moved into the area, attracted by cheaper land prices. Approximately 70% of the population claim Maori descent, and the population profile is a young one, with youthful families predominating.

4.3. HOKIANGA HEALTH CONTEXT.

The Hokianga was the first of 12 Special Medical Areas to be granted such a status in New Zealand. These were set up by the First Labour Government after the Second World War, in remote areas with scattered populations and where private practice was not economically viable (Kearns 1991). They were introduced primarily to improve access to health care in terms of both distance and financial costs. The Special Medical Areas (SMAs) tended

⁴Currently, Hokianga Health Enterprise Trust have approximately 9,200 people on their register (Bridget Allan, pers. comm.). The reason for the discrepancy is that people show a reluctance to be recorded in the census surveys, mainly due to anti-authority opinions (J. Field, pers. comm.).

to be isolated, rural and socio-economically deprived, and in the North Island, they had large Maori populations. These conditions still exist in the Hokianga (Kearns 1991: 420, 1998; Woods 1995: 22). Unlike other areas of New Zealand, doctors in SMAs were salaried and health care was free to residents so that financial and geographical barriers to health care were minimised. Health care services were thus brought into isolated areas and by having salaried medical officers, patients did not have to pay for these services. The health reforms of the 80s and 90s (outlined in Chapter 3) seemed certain to implement charges for the Hokianga. However, through a localised politics of resistance (Kearns 1996; 1996a), residents formed a Charitable Trust. Originally, the Trust was set up to try and stop government attempts to institute user charges for prescription pharmaceuticals (Woods 1995: 22). It managed to take charge of the pharmaceutical budget for the region after a six month trial followed by an 18 month extension (ibid.). In 1993/4 the Trust took over the management of all health services in the Hokianga (HHET 1994: 8). By June 1994, the Trust could declare its significant activities as Primary Health Care Services, Disability Support Services, Pharmaceutical Services, and Dental Services (HHET: 1994: 32). These services are still provided free of charge.

In terms of health policy and practice, the Hokianga is unique in New Zealand. It is the only area that has a community based trust that delivers free primary health care services to its population. The Hokianga Health Enterprise Trust (HHET) has 20 elected Board members, and up to 10 co-opted members. In terms of ethnicity, the Trust Board is representative of the people of the area. (At the time of writing, there are 18 Maori members of the Board.) The Trust is accountable to Hokianga people through the Board - there are two Trustees from

each community in the Hokianga. The monthly meetings are open to the public and the trustees are obliged to report back to their own communities. HHET recognises *tikanga* (customs, correct procedure, authority) and *mana* (authority, control, prestige) in the region, working within the framework of the Treaty of Waitangi. It remains committed to providing a culturally appropriate service for its clients. In the 1994 Annual report, the Treaty of Waitangi is acknowledged as a founding document for Aotearoa/New Zealand, and the Trust explicitly seeks to work within the articles of the Treaty in all its activities. Moreover, the Trust's philosophy explicitly encompasses a commitment to providing culturally appropriate services in its third article, that is '...ensuring equity of services within the Hokianga, recognising one people (*te iwi o Hokianga*) but providing for particular cultures and needs (*Na te mea he "iwi kotahi tatou" i tutuki ai*)' (HHET 1994). Services acknowledge *whanau* (extended family), *wairua* (spirituality), *hinengaro* (mental aspects) and *tinana* (physical aspects). Hauora Hokianga recognise that *whanau* (family) and care givers are integral to the healing process. Cultural safety delivers the services in a way that maintains the client's physical, social, cultural and emotional well-being. *Whanau* participation is actively encouraged so that the client and their family/*whanau* members are happy with the way in which the service is provided.

Negotiating access.

I believe that research ought to be beneficial to all those involved, and this attitude in large part shaped this project. Pomeroy (1993: 268) has argued that all too often, research reports follow what she terms the 'vulture' approach, where findings having little relevance to the researched. A researcher's own

plans should therefore not guide the research process alone. They must be sensitive to what is and what is not relevant as well as accessible (Hammersley and Atkinson 1995: 44). Issues of access are thus crucial in shaping a research project like this. Going to a new country to undertake research is always a risky venture, not only because of time constraints, but also because of the difficulties inherent in setting up contacts prior to arrival. In the months preceding my arrival in New Zealand, I had regular contact with Dr. Robin Kearns of the Geography Department at Auckland University, discussing possibilities and options once I arrived. Once in Auckland, we were able to discuss these ideas more fully, and we decided that the first step was to negotiate access to working in the Hokianga. Dr. Kearns has close research links with the area and he was able to set up a meeting between myself and the Chief Executive Officer (CEO) of the Hokianga Health Enterprise Trust (HHET). This took place in November 1994. Also present were the Trust's two Principal Nurses⁵. I outlined my research interests and my eagerness to do something that would be useful for those participating in the research and we discussed various possible topics that I could investigate. After careful discussion, we agreed that one potentially valuable piece of work might be to evaluate a particular aspect of health service delivery, with a view to improving it for both clients and staff. It would also enable me to listen to specific health discourses, which could then be put to use in the policy planning process. After discussion with Hokianga's Community Health Nurses, it was decided that I should conduct a qualitative evaluation of the Home Support Services provided by HHET (see Sections 4.4 and 4.5 below).

⁵I am indebted to Dr. Robin Kearns at the University of Auckland for this introduction. Without his help, this project would not have got off the ground.

By Home Support Services, I mean home help - not top of the political agenda, but nevertheless, critical to the lives and well-being of a large proportion of the elderly population, and a valuable source of income to the employees of the service.

This was only the first part of the access issue as I had next got to make contact with those involved in the Home Support Service. It was suggested that because I was unknown to the community, it would be best if a rather formal approach be taken. Two letters were therefore mailed to those who provided or received Home Support Services (See Appendix 3). One was from the CEO of the Trust, introducing me and explaining why an outsider was a good choice for the project. The second letter was written by me, about my background and what the research was for and how it would be used. At the bottom of the first letter, a reply slip was printed. The reply slip gave people the choice of whether or not to participate. They were to mail these back accepting or declining the invitation to take part⁶. After that, I simply had to sit back and wait for the replies to come in.

4.4. HOME SUPPORT SERVICES AND THE HOKIANGA.

There is a small but growing international literature on home care, suggesting the increasing significance of this field. Given the ongoing debates in hospital versus home care, and the restructuring and rationalising of many health care systems, this growing interest is hardly surprising. International research covers all aspects of home care services. For example, in Canada, Williams

⁶I am grateful to HHET for letting me use their computers and for paying for the research costs including printing, stationary and postage.

(1996) has shown how long-term health care policy has contributed to geographical inequalities in home care services in Ontario. In the UK, Redmond et al (1996) have argued that older people receiving home help have higher levels of unmet health needs than those not receiving home help, and constitute an 'at risk' group. They conclude that using the home help register is a valuable method of identifying a group of individuals with significant levels of unmet health needs. This assertion is supported by Ranhoff and Laake (1996), who argue that home help clients in Norway represent a particularly frail group of elderly people. In Scotland, Myers and MacDonald have examined the gap between the ideal of user and carer empowerment, and the reality of day to day practice (1996). And Ottewill et al (1996) have reported on the right to be given a bath at home, and the age-old argument of to whom this responsibility belongs - community nurses or social services. This debate might seem trivial, but it certainly is not from a client's perspective. Arts et al (1996) have examined the trend for home help services in the Netherlands to become increasingly professionalised. In New Zealand, the subject of home help has attracted scant attention so far. The only major piece of work to consider it in any detail was the 1972 national survey of the elderly (Salmond 1976). More recent work concentrates on urban areas only, such as Christchurch (Holmes 1981; Malcom and Higgins 1981), Auckland (Gilbert 1991), and Wellington (Jack and Neale 1987).

As such, rural people receiving home help - or needing it - is an under-researched area in New Zealand (see also Joseph and Chalmers 1995). At both a local and international level therefore, evaluating Hokianga's home help service is a relevant and significant study. In addition, it might also tell us

something more generally about wider social relations, for example, whether there are 'racialised' or gendered discourses of home help, how people manage their chronic disabilities on a day to day basis, or how New Zealand society deals with increasing age and infirmity; for example. These kinds of issues are exactly the ones that the biomedical model has been unable to deal with and this is why I am keen to explore illness and disability through other theoretical concepts and literatures. I hope that in doing so, I will be contributing to a more critical and nuanced medical geography.

At national and regional levels, discourses of home help are deeply embedded (nearly submerged) within the wider context of health care provision and politics. Following the Health and Disability Services Act 1993, Regional Health Authorities became responsible for purchasing the following services: primary and secondary health, disability support, and public health. Home help, as a tiny subset of disability support services, is therefore one seemingly insignificant fraction of the overall picture. But national health policies often treat a population as homogeneous and this causes considerable difficulties when dealing with the reality of diversity. Although in New Zealand there is considerable effort to make policy acceptable to Maori and Pakeha, rural and urban, difficulties inevitably arise. Gubrium argues that 'policy typically glosses over localised interpretations, treating them as hindrances to successful general application' (1989: 94). National and regional discourses of home help centre around 'objective' and quantifiable measures in an attempt to ensure that services are accessible, acceptable, effective, safe and efficient (Ministry of Health and North Health 1995). Although policy pays scant attention to local peculiarities, these were clearly exposed in lay narratives. I examine these

differences in Chapters 6 and 7. In the process, some of the potential discrepancies between a market oriented policy and the reality of lived experience were also highlighted. This showed that measuring the categories of quality, quantity, efficiency or effectiveness were not as clear cut as policy implies; nor were they necessarily mutually exclusive.

In 1994, under contract from the Regional Health Authority (North Health), Hauora Hokianga took over Home Support Services from The Department of Social Welfare. As its name suggests, the Home Support Services serves any member of the community with a long term disability, who needs extra help at home. Hauora Hokianga has responsibility for the assessment, service co-ordination, and service provision for their population. They felt it was important to carry out an evaluation to ensure standards were being maintained in this climate of sole service provision. Through the Home Support Services programme, clients can receive domestic services, such as cooking, cleaning, laundry and shopping and/or personal services such as help with personal hygiene requirements and dressing. Attendant care is a service for people between 10 and 65 years of age who have a chronic disability or condition and require personal care services. Everybody over the age of 65 comes under the Home Support umbrella, regardless of the type of services they get.

The referral.

Anybody can refer someone else to Home Support Services, if they think they are having trouble managing at home. Most frequently, this referral comes from the Community Health Nurse, but it is not unusual for clients to refer

themselves, or be referred by their GP, a relative, neighbour or friend. The Community Health Nurse visits once the referral is made in order to carry out an assessment (See Appendix 2 for the assessment guidelines). At this visit, the nurse and client (and *whanau*/family member or other representative of the client if desired,) can discuss the types of difficulties the client has and the options available to ameliorate some of the strain. Choosing a care giver is the next step in the process. It is Hokianga Health policy that family can do personal cares, but not domestic duties, a point I return to in Chapter 7. The care giver may be chosen in a number of ways, and their selection understandably requires much skill and tact. Once the care giver is chosen, and both client and care giver are happy with this, the assessment documentation is returned to Hokianga Hospital for processing. In the documentation is the Community Health Nurse's recommendation of how many hours a week a client needs. At the processing stage, this requirement is either approved or declined. If declined, the problem is usually a lack of hours available for allocation. The most common reason for this is that the allocation of money and hours from the Regional Health Authority (who pay Hauora Hokianga to run the service,) is not enough to stretch to all the needs (whether actual and perceived) of those receiving Home Support Services. The outcome is generally a case of fewer hours being allocated than requested, and the case to be reviewed in three months time.

Once the hours allocation has been approved, the services a client can expect to receive are then mutually agreed between the client, the caregiver, and the Community Health Nurse. This agreement is formalised into a care plan that outlines the duties and responsibilities of the care giver (see Appendix 2). Duties, and their frequencies, are written on the care plan, so that there is a

common understanding of what is going to happen when the care giver comes into the client's home. This assessment process is reviewed annually or more frequently if necessary.

4.5. WHO SERVES, AND WHO IS SERVED BY HOME SUPPORT SERVICES?

In order to undertake a successful evaluation, knowledge about Home Support Services was needed. This section therefore briefly describes the variety of people who receive help at home, and how the service is implemented. These people are often frail and elderly, with chronic, long-term disabilities such as mobility difficulties due to strokes, or limb amputation. There are also some younger people getting help at home, for example mothers with special needs children receiving Home Support, and young disabled people receiving Attendant Care. The evaluation study invited every client receiving Home Support Services, as of March 1996, to take part in the research. In all, there were 61 clients receiving help. Of them, 65 (74%) were over the age of 65 and 16 (26%) were under 65. 18 (30%) were male and 43 (70%) were female. Most are elderly widows (21 or 34%). The majority of clients 67% (or 41) are Maori, 32% (or 19) or are Pakeha, and 1 is a Pacific Islander. To a greater or lesser degree, these people have restricted ability to carry out their activities of daily living.

4.6. THE RESEARCH PARTICIPANTS.

38 of the clients (62%) were actually interviewed: one Pacific Islander, 24 Maori (64%) and 13 Pakeha (34%), in keeping with the wider ethnic picture of the Hokianga. These interviews were conducted at the client's home at a convenient time. I visited Pakeha homes on my own; my colleague and I visited Maori and Pacific Island homes together. It should be noted that the general frailty of clients became increasingly evident as the interviews got underway. 4 Clients ended up being interviewed as inpatients at Rawene hospital, and several other clients could not be contacted as they were inpatients in hospitals as far afield as Whangarei, and Middlemore and Green Lane, in Auckland. There were also four deaths during the study's duration, and the following calculations have been adjusted to account for those deaths.

61% of Maori clients and 68% of Pakeha clients kindly spared us the time to visit and chat to them about Home Support Services. Most of the clients are elderly, with age-associated, chronic ongoing health and disability problems, such as strokes and arthritis. 4 of those interviewed suffered from quite marked memory loss, they have therefore not been included in the following statistics, but where possible, their stories have been used in the qualitative part of the study. There are also a few younger people who receive Attendant Care Services, for example those with special needs children, or young disabled people. In the sample interviewed, there are nearly five times more women than men. In gender terms, this is not a representative sample of the total number of clients, where the ratio of women to men is nearer 2.4:1. Although efforts were made to maintain a representative sample, in the case of gender it was simply

not possible. (This could affect the study results, reflecting a bias towards women's opinions. However, following analysis of the data, it seems that the opinions and stories shared with the researchers did not tend to vary widely between men and women.)

In March 1996, there was a total of 40 care givers employed by Hauora Hokianga. Appendix 5 shows the breakdown of care givers by ethnicity and gender. Most of the care givers are women whose families are either of school age or grown up. Of the 40 care givers invited to take part, 14 (11 Pakeha, 3 Maori) consented by mail. All of these were interviewed. In addition, 3 others were present at their clients house when their clients were interviewed. Their contributions to the conversation are duly noted. In order to get a more representative sample, however, 9 more Maori care givers and one Pacific Islander were telephoned and invited to take part. Altogether, 11 Pakeha, 14 Maori and one Pacific Islander care givers participated. Ultimately, 44% of care givers joined in the study (44% of Maori care givers and 68% of Pakeha care givers).

4.7. THE POLITICS OF RESEARCH.

I was nervous about working in the Hokianga. This was partly fear of the unknown, and partly because of my experiences at the Asia Pacific Conference on the Social Sciences and Medicine, that I outlined at the outset of Chapter 1. In addition, a conversation I had with a Maori professor at the University of Auckland unsettled me further. The diary entry for Friday 1st December 1994 reads:

‘Not the most enthusiastic meeting I’ve ever had. I’m writing this two hours later in the hope that I’ve got over the experience. I explained [to the professor] what I was interested in [but] was deliberately vague as I’m not too sure what exactly I’d be researching in the Hokianga. The comments I came away with were, “Don’t let people push you around too much as you might waste time on little itchy-bitsy projects” and “It sounds more like a project for a BA rather than a PhD”. How’s that for encouraging! I mentioned my interests in indigenous people and their relationships to land and to health - [the professor] said I wouldn’t get much back from people - they didn’t think in those terms. She suggested it wasn’t really a question worth asking. I also touched on empire/legacies/postcolonial studies which at least wasn’t shot down in flames. On mentioning Maori-Pakeha discourses, [the professor] thought I wouldn’t find any difference, “We’ve been colonised for years, we’re pretty well assimilated, we’re just like you, you know”...On the good side, she did say she thought I was approaching it with a good attitude and wished me luck with it...’

These negative reactions weighed rather heavily on me. What if my thesis was only BA standard? What would Hokianga people make of an English woman who was digging around for very personal information? Would they even be prepared to talk to me? Should I stick only to ‘white communities’? What if I couldn’t get enough information for my thesis? I discussed these concerns with Dr. Kearns and The CEO of Hokianga Health Enterprise Trust and I am grateful that they were both supportive and encouraged me to carry through my convictions. And at least I was told that I was approaching it with a good attitude. I reflected on these experiences for a long time, and realised that in order to produce an honest thesis, I should address these matters explicitly.

Representation.

Recent years have witnessed a growing awareness of the politics of research and in particular, questions of representation, positionality and

reflexivity. However, these terms themselves sometimes go unexamined. I think it is important to evaluate them and the ways in which they are used, so that the thesis is explicit about the ways in which these concepts are used, and is sensitive to one of the major current predicaments in social research. Duncan and Ley (1993: 2) assert that the task of scholars is to represent the world and that until recently, this has not been problematised. The question of how we should represent the world has, until now, been taken for granted. But charting any space (social, physical, or cognitive) raises questions about the adequacy of representation although according to Hall (1997), this notion (of representation) is an extremely slippery customer. He argues that on the one hand, it can be used simply as another way of talking about how one perceives a reality that exists 'outside' the means by which things are represented: 'a conception grounded in a mimetic theory of representation'. On the other hand he points out that the term can also stand for a very radical displacement of the unproblematic concept of representation. Thus, '...events, relations [and] structures do have conditions of existence and real effects outside the sphere of the discursive, but that it is only within the discursive, and subject to its specific conditions, limits and modalities, [that] they have or can they be constructed within meaning'.

On a practical level, questions of representation centre around whether we can (indeed should we even be trying to?) adequately represent the subjects of our research. As Hoy and McCarthy point out, '...who gets to represent whom, when, where, how, and for what purposes is not without political consequences' (1994: 87). For example, European representations of the other have been far from benign. In particular, notions of race have promoted

constructions of distorted cultural representations (Duncan and Ley 1993: 6)⁷. Cultural representations help form the images we have of others; if assimilated by those others, they will influence the images they have of themselves as well. In addition, they get embodied in institutions and inform policies and practices. In these ways, various academic disciplines, notably anthropology and geography grew out of the colonial situation and reinforced it with images of Otherness, including the inferiority and irrationality of non-western peoples. These issues are of particular importance for the thesis, and I have tried hard not to reproduce this situation during this research project.

Rabinow has discussed representation and its connections with epistemology (1986: 234). He describes how Foucault (1970) showed that the problem of 'correct' representations has affected many social domains and practices. For Foucault, the problem of representations is part of the wide spectrum of diverse and interrelated social and political practices that constitute the modern world, including its characteristic concerns with order, truth, and the subject. The domains and practices Foucault uses to illustrate his arguments extend far and wide, from disputes in botany to proposals for prison reform (Foucault 1970, 1977; Rabinow 1986: 234-239). Drawing upon Foucault, Rabinow argues that we must begin to think in terms of a profusion of systems of representation that are products of discourses, always and inevitably tied to social practices (1986: 239-41).

⁷However, an almost infinite number of questionable representations could be implicated in the discourses of exclusion, for example, sexuality, sickness religion and gender.

Marcus and Fischer (1986) have highlighted the 'crisis of representation' in ethnography and anthropology and this has had a wide impact on the social sciences in general. At a theoretical level this predicament questions how we can adequately represent reality, without distortion (Berger and Luckmann 1967). Because representations are historically and geographically specific, the author is implicated in the text and thus cannot be neutral or value free. Marcus and Fischer therefore call for an abandonment of mimetic theories of representation, arguing that language is not a transparent medium. As a result, our representations can only be partial truths (Clifford 1986). In addition, Marcus and Fischer have emphasised the importance of considering issues such as contextuality, the meaning of social life to those who enact it, and the explanation of exceptions rather than the regularities observed (1986). These need to be considered because they make problematic what were previously taken-for-granted 'facts' or certainties, on which the validity of paradigms rested. Problems of description have thus become problems of representation and the 'crisis' has arisen from the uncertainty about whether social reality can ever be adequately described. These issues have been explored in most depth by philosophical and literary theories of interpretation and because all perspectives and interpretations are subject to critical review, they must finally be left as multiple and open-ended alternatives (ibid.: 14).

In a sense, the history of human geography is also the history of representations. Maps and texts about other places and peoples have long been the mainstay of the discipline (for a critique, see for example, Harley 1988, 1992; Jacobs 1993). Duncan and Ley (1993: 2) have described four modes of representation in human geography. The first two, descriptive fieldwork and

positivism are similar to each other in that they strive to achieve mimesis. But in addition to the geographical sites to be represented, we must also be mindful of the site from which that representation emanates - the geographical, cultural, political and theoretical viewpoint of the author (Duncan 1993: 39-44). The other two modes of representation Duncan and Ley describe are attentive to this claim. The third type of representation they describe is interpretive, with its origins in hermeneutics. Unlike the first two positions, this approach acknowledges the role of interpreter and accepts that interpretation is a dialogue between the information gathered - other places and other people, and the researcher who is embedded in institutional and intellectual relations. Mimesis is therefore impossible to achieve, because the interpreter is present in the textual copy. The fourth type of representation takes a postmodern stance and attacks the notion of truth-searching and mimetic representation. The postmodern opinion critiques the Enlightenment project, particularly objectivity, meta-narratives, and rationality. This position shares the hermeneuticians' critique of mimetic representation, but goes further by decentring the elitist sites from which representations often originate, most notably Western, white male intellectuals. The monopolistic representational control by western male academics has become displaced with the introduction of a polyphony of voices. The diffusion of representational authority into numerous sites including women in academia, non-academics within our own culture and people from other cultures, has eroded the political authority and ascendancy of a single author, and has shown that a goal of mimesis is untenable. Moreover, because mimesis cannot be attained, a postmodern style includes experimenting with writing (and other ways of presenting material such as video,) so that representations become

ambiguous, incomplete and open-ended, evoking ideas and interpretations, rather than trying to reproduce reality.

These last kinds of ideas resonate well with what Thrift refers to as non-representational theory, where thinking and understanding is always “hesitant, partial and situated” (1996: 4). The different schools of thought within this tradition argue that representational models of the world are unsuccessful because their focus is ...“‘internal’, and their basic terms or objects are symbolic representations” (ibid.). In contrast, non-representational models of the world have an ‘external’ focus, and basic terms and objects are shaped into actions and interactions. There are several features of non-representational theory, which have been captured neatly by Thrift (1996: 6-7). He argues first, that non-representational ways of thinking shed a critical light on theories that claim to represent some naturally present reality. Instead, they suggest that it is *practices* that constitute our sense of the real. Secondly, non-representational theories give credibility to familiarity and know-how, or as Thrift puts it, ...“ t[o] practical expertise...[non-representational theory is] concerned with thought-in-action, with presentation rather than representation’. Third, that the focus on ‘thought-in-action’ emphasises the significance of the particular moment. This in turn suggests that representation is always a part of presentation. It is played out in a specific context, which invites only particular kinds of presencing practices. Fourth, non-representational ways of thinking and doing are concerned with the entire body, with all the senses and not just privileging the visual, which has been the case with representational traditions. Fifthly, this concern with *all* the senses invites a critical reappraisal of the ‘linguistic turn’ in the social sciences. The linguistic turn has focused attention

away from the embodied and situated nature of human practices, because too often it has focused solely on 'the verbal-cum-visual' at the expense of the other senses - touch, hearing, smell, taste. It has also neglected the importance of body language and movement. Sixth and lastly, non-representational theory is concerned with a different notion of 'explanation'. Thrift likens this type of explanation to

“...understanding a person, a phenomenism of character which involves, more than other approaches, empathetic and ethical components...[u]nderstanding is not so much, then, about unearthing something of which we might previously have been ignorant,...as it is about discovering the options people have as how to live” (1996: 7-8).

I have been influenced by interpretive and hermeneutic approaches to representation, as well as strands of postmodernism and non-representational modes of thinking, writing and doing. As a result, at various points, the thesis draws from all these perspectives. For example, I have tried to be open about my role as interpreter, and my own social and intellectual circumstances, thus explicitly positioning myself in the text. But I have also included other voices in an attempt to diminish the prominence of my author's role. Interview and diary excerpts not only describe and interpret what was heard, but also pay attention to body language, movement, positioning, and other senses and sensations. My approach to the study, and my interpretations of the stories I collected, are not concerned with 'explanation' in the traditional sense, but in “...discovering the options that people have as how to live” (Thrift 1996: 8).

The postmodern situation is characterised by the recognition of a plurality of discourses (Angus 1993: 184) This, together with the representational crisis has led researchers to search for alternative ways of

undertaking and writing up their inquiries. Agreeing that ethnographic encounters have always been the products of complex, situated, ambiguous, and conflictual interactions, many researchers no longer try to suppress this behind an ordered objective account (Hoy and McCarthy 1994: 87). Instead, they situate themselves explicitly in the text, emphasising the 'messiness' of both everyday life and the research process. One way in which the authors' former position of superiority and objectivity has been diminished is to produce projects where other voices (as well as the authors') are included in the text. This is the notion of polyphony. Usually, these voices belong to the research subjects. Polyphonic texts have two basic features (i) the simultaneous combination of many voices, each of which carry equal weight and merit within (ii) a "coherent texture", where the voices are interdependent (Crang 1992: 430). These two features create a tension between unity and disunity, independence and interdependence, providing the space within which polyphonic texts can be generated. Polyphonic texts allow those being represented to '...speak in their own voices, tell their own stories, challenge the ethnographers' views, [and] offer alternative suggestions', (Hoy and McCarthy 1994: 87). Crang suggests that true polyvocal ethnography is '...otherness represented in nonessentializing, nondichotomizing, noncentralizing ways, [and] that the bearers of otherness are themselves allowed to participate fully in its textual construction' (1992: 437).

Polyphonic projects are often argued to be collaborative endeavours, because the subjects themselves have shaped the text as much as the author. However, the degree of help afforded by the subjects is usually determined by the author. On the one hand, it can range from the simple inclusion of statements made by research subjects. On the other hand, it can extend as far as the

participants being actively involved in writing up the research, perhaps even deciding what information is included in the final text. Frequently, projects lie somewhere between these two poles. Often, their position is determined by the type of research being undertaken and the constraints under which the researcher is operating. This thesis is no exception. For example, although I chose what to include in the final text of the evaluation, participants were at least invited to attend feedback seminars and comment on the finished document. I could not allow participants to co-write the evaluation study for Hokianga Health Enterprise Trust, because of the potentially damaging input vested interests might have. (I describe this study in more detail later on in this chapter.) As I knew no-one in the area, I was unaware of the intricate politics and relationships that existed, whereas the participants were local and therefore probably would have. And although I have used the evaluation work and participants voices in the thesis, I alone have written it as I am operating under university regulations in order to gain a PhD.

Polyphonic texts are an important, if somewhat problematic endeavour. Within geography, Crang has put forward the most detailed examination of their potential (1992). He argues that ideas of polyphony occupy an important place in current debates both within geography and cultural theory, and that they are closely related to how researchers might and do represent those they study. This calls into question what Crang terms 'representational poetics and politics' (1992: 428). The poetics of a text are bound up with the way it is written. The composition (overall structure), its genre (for example, novel or poem) and style (the less codified aspects of textual labour) are all part of the creative labour of writing, and all affect how the text represents its subjects and is interpreted.

There is also a politics to who can write and therefore who represents. Here Crang invokes the work of Said (1978) who argued that those being represented in the text do not represent themselves. Furthermore, these subjects tend to be represented as coherent and constructed categories of 'Others' by those doing the representing.

Crang (1992: 439) lists five possible objections to practices in academic writing: (i) is polyphonic writing in geography actually new or just a fashionable label? (ii) do discussions of polyphony overly restrict our conceptions of representational politics? (iii) that authorship and its representational authority remain problems that polyphony does not solve (although, as Tyler has pointed out, polyphony is a means of perspectival relativity and not just an evasion of authorial responsibility or a guilty excess of democracy (1986: 123)). (iv) what happens to academia's rhetorics of 'truth' if polyphonic contradictions are embraced? (v) are appeals to polyphony as much about repositioning factions of the representing group of academics as they are about empowering the represented? Feminists, for example, have objected that the 'crisis of representation' within anthropology has replaced the privilege of a single (male) ethnographic authority with a relativist notion of 'many voices' at the very time when women were first coming to voice. Thus female voices are implicitly denied (Jackson and Penrose 1993: 14). Similar critiques have also come from postcolonial authors (see for example Bhabha 1994a).

Nevertheless, polyphonic texts, Crang argues have two main possibilities. In rethinking the relations between the researcher and the researched, they might first allow the representation of otherness or of cultural

difference without constructing coherent and 'residual' others. And second, because the term has become associated with the restructuring of the politics surrounding the representations, extended voices and co-authorship become real possibilities. I believe that there is a necessary and strategic value to representation - as a means to an end. In this case, representations are necessary for the purpose of a PhD and for evaluating the home help service in Hokianga, described below. However, a critical examination of the techniques I am using to represent the research subjects reveals the problems of this particular way of doing things; like other modes of representation, it is not problem free. But I have tried to address these concerns in order to show that ethnography and a polyvocal text might, in this case, be useful, constrained as it is by more traditional issues such as academic expectations and university rules for the writing of a PhD.

Positionality and reflexivity.

Jackson and Penrose argue that one way of facing '...th[e] problematic positioning of self and Other has been a determined effort to throw off the cloak of scientific objectivity and to explore the consequences of our partiality' (1993: 13). This involves us accepting firstly that knowledge is situated, and secondly, taking responsibility for our own positions, with regard to the subjects of our inquiries. This means researchers must be clear about the "politics of position", and the implications this has for academic work (ibid.). Any piece of work must therefore acknowledge the author's position in relation to those researched - a position that has developed from post-colonial anthropological literatures (Clifford and Marcus 1986). Academics often argue (rightly) that they are in a

superior position of power compared to those they work with and this affects the research results. In my opinion, positionality should be an ongoing research theme, woven throughout the whole project, rather than acknowledged in a couple of paragraphs and buried somewhere in the text. In the case of this research project, although I have called attention to it here, notions of positionality are included throughout the thesis where appropriate. Positionality is usually understood in terms of class, gender, 'race'/ethnicity, sexual preference, and community. They are '...crucial elements in defining how particular differentiated discourses arise...and how such discourses are put to use as part of the play of power' (Harvey 1993: 40). It is therefore easy to see why questions of positionality are important for this project.

The links between positionality and reflexivity are close. As no discourse or knowledge is value-free, it is important for researchers to be aware of their position as producer and reproducer of certain discourses and practices, and the personal commitments and values inherent in the use of such discourses and practices. This awareness is often referred to as reflexivity (Lupton 1994: 13-14). Like other keywords of this thesis, the term reflexivity has many different meanings and interpretations. Bonnett describes it as a "famously difficult idea" defining it as "the social self-consciousness of social process". The opposite of this, he asserts, is unreflexivity, or common-sense forms of consciousness (1993: 164). Turner has argued that 'interdisciplinarity' requires reflexivity, in this case an awareness of the historical and social setting of scientific concepts (1992: 127). Fox characterises reflexivity as

'...analysis which interrogates the process by which interpretation has been fabricated: reflexivity requires effort to

describe or represent [and] considers how that process of description was achieved, what claims to 'presence' were made, [and] what authority was used to claim knowledge...' (1993: 163)

In my own work, I use the term as a reminder to be self-aware, accountable, responsible and critical of my actions and words. It also enables me to acknowledge my presence both in the text and in the interpretive part of this work. Critically analysing discourse requires me to be constantly reflexive, which includes examining the political nature of my own use of language and discourse. In addition, an analysis of the discriminatory or stereotyping characteristics of discourse and practices; an interrogation of their normalising assumptions; and an examination of the multiple and alternative forms of subjectivity, rationality and bodily practices that are available to the research participants are also topics that merit serious attention (Lupton 1994: 13).

The researcher will always influence the research setting. Many evaluation studies emphasise the need for an outsider to come in and undertake the evaluation, to reduce any bias inherent in the project. This was the reason that Hokianga Health Enterprise Trust had asked me to undertake the evaluation. It is often assumed that an outside evaluator permits more independence, objectivity, and credibility than internal evaluators because they have no stake in the programme (Patton 1986: 309-310). In the last ten years however, this opinion has changed for several reasons, for example, outsiders know less about the politics and nuances of the local situation, and, when the evaluation is finished, they may take a great deal of knowledge and insight with them that then becomes lost to the programme. However - and this was HHET's argument - outsiders *can* assist stakeholders to identify the problem and reach a solution

without getting bogged down by local politics and relations (Pomeroy 1993: 269).

In terms of my own positionality, I am fascinated both by health and cultural issues. My training and post-registration experiences as a nurse in various capacities has served to strengthen this interest. Moreover, it has given me a practical understanding of the ways in which medical and allied professions are trained and work together, as well as a knowledge of medical jargon. My training as a social scientist has often been at odds with my biomedical nurse's training because social science, as I see it, accepts the contingency and simultaneity of lived experiences more readily than biomedicine. It also questions the status quo, whereas biomedicine is inherently conservative. Furthermore, my social science training is not nearly as reductive and constricting as my nurse training was. What I am trying to do now is to combine these two strands of my training productively, in order to think through new ways of thinking about health concerns. However, a white woman talking with those who identify themselves as Maori may be accused of ethnocentrism, continuing colonial domination and actually reinforcing notions of otherness. But because I have included both Maori and Pakeha narratives in this study, I hope to withstand these criticisms. This, of course, was not the case at the Asia Pacific Conference on Social Science and Medicine, where two Maori delegates took me to task most decidedly. Yet in the Hokianga, I experienced a totally different attitude. Perhaps this was because of the different subject positions occupied by the delegates at the conference, in contrast to those who live and struggle in the Hokianga, where although ethnicity is very much a political issue,

it was not personally threatening in the way I had experienced previously⁸. Moreover, when I brought up my own concerns about asking potentially embarrassing/culturally inappropriate/offensive/unsafe questions, in the Hokianga, Bridget, Chief Executive Officer of the Trust told me:

‘Just ask what you like, because hey, everyone knows you’re from out of town and ignorant...you’ll be much less likely to offend than someone who should know better...’⁹

Questions of power and gender relations in the interview process must also be considered. In my experience, being female is a distinct advantage when it comes to interviewing, as women are often perceived as somehow less ‘threatening’ than a man. Power relations between interviewer and interviewee thus may have the potential to become somewhat more balanced. Interviewee’s perceptions of male and female researchers may affect the research results if narratives are structured according to what they think the researcher wants to hear, or if they are uncomfortable with the person they are talking to. This is particularly true of health research, where often the answers can be determined to a large extent by the question asked (Kearns 1991: 424). As a woman, I expected to get different receptions and be given different health stories than if I were male. Women, I thought, may be more willing to share personal experiences with me because I am also female. It might be assumed that I am likely to have had similar experiences or be able to empathise in a particularly feminine way.

⁸In a way, this makes me wonder who is it having the ‘crisis of representation’ anyway?

⁹Diary 1, Entry for 21 November, 1995.

Similarly my age and 'class' will have influenced the research experience and outcomes. Age differences between myself and others I talked to may have modified the information given to me. If, for example, people thought I was too young to appreciate what they were talking about, they may have withheld certain information. In the event, it was the older (post-menopausal) women that spoke most freely about their bodies and particularly about menstruation, because, as Sarah, my key informant said, "They're past all that"¹⁰. Ideas of 'class' may also have structured the narrative I heard (or indeed - didn't hear). Working with marginalised populations means that perceived and real social differences may be felt all the more acutely and this is something I had to be constantly aware of. From my own perspective, it meant working towards an understanding of everyday life in rural New Zealand, for both Pakeha and Maori populations. This was my starting point for trying to reduce potential discomforts with social distance. In addition, attitudes were and are of crucial importance when doing any social research. It is a fine line that divides superior attitudes, self-righteous predispositions and a desire to do something useful. There is always the danger of being accused of a certain amount of voyeurism in this kind of project, where the possibility remains that this type of work may only emphasise social differences and life-chances. Questions of potential disempowerment therefore loomed large. In an effort to remedy this, participants were invited to keep their tapes and transcripts; attend feedback seminars, and given the opportunity to alter anything they had said previously. The report for HHET was also made freely available to the research participants.

¹⁰Diary 2, Entry for 28 May, 1996.

Questions of academic training also need to be addressed. Involvement in university life is often viewed as a privileged middle-class affair, and this can have a serious impact on the nature and quality of research results. Responses to interviews are known to be affected by the many attributes of the researcher (gender, or 'class for example) one of which is educational achievement. This is especially important when researching disadvantaged populations of any sort, because often, the researcher has a more 'westernised establishment' educational training which is often perceived by both themselves and others as 'better' than other types of knowledge. This then has the potential to set up a skewed power relationship, where (often unwittingly) the researcher might act in a spirit of superiority. While I could not get away from the fact that I am university trained, I did try to ease potential tensions. One way was by my attitude and appearance. Dressing appropriately certainly helped - turning up in gumboots and casual clothes put people at ease. I also found that being a good listener and relaxed with people helped others act in a similar way. But the biggest ice-breaker was that I was pregnant. This seemed to automatically break down barriers, particularly with the women participants and especially when I was suffering with rare moments of morning sickness¹¹.

There is no doubt that the researcher will impact to a greater or lesser degree on the research setting, the form conversations and interviews take, and therefore the overall results of the study. Researchers have to do their best to make the participant feel comfortable and establish a good rapport early on in

¹¹However, with the benefit of hindsight, and trying to write a thesis with a baby around, I would not advise others to try it!

the interview. Their attitudes, modes of dress and general appearance, ethnicity, gender and age will all influence how a participant responds to them. Whilst some measures can be taken to make participants feel more comfortable (appearance for example), others cannot be changed (gender, age, etc.). In this study, dress was casual but neat, so as not to appear overly formal. My colleague and key informant, Sarah, is a Maori *whaea*¹², who is highly respected in the community. This added much legitimacy and import to the research. It is hoped that this enabled Maori clients to voice their opinions in a safe and supportive environment, and in Maori if they wished.

4.8. CONCLUSIONS.

These issues are important because they made a difference to the methods, 'results' and analyses of the project. In terms of methods, I was open about my background, and the purposes of the research; I tried to position myself openly and honestly. I also encouraged participants to lead the interviews, rather than firing lots of questions at them. This meant that the content of the interviews often diverged from their original purpose and getting back on track was tricky at times - I did not always succeed. In terms of results, these were influenced by how people reacted to me. I tried to be as relaxed and relaxing as possible, so that people would feel comfortable talking with me. In some cases this worked well, in others, not as well. Some interviews were therefore more 'successful' than others. In terms of analysis, I was triangulating qualitative and

¹²A mother or aunt, but to the community, rather than/as well as immediate family. Members of the age group who are not yet old enough to be tribal elders, or *kuia*.

quantitative information, in order to provide the evaluation for Hokianga Health. I found the evaluation relatively straightforward, in that I only had to write the report on the information I had gathered. The difficult part has been trying to do two things with the information: write an evaluation *and* a thesis. I found that by trying to do the evaluation well, I had to let some issues that I was interested in go by the wayside: these are reported on in subsequent chapters.

In this chapter, I have tried to pull together the very diverse threads and underlying themes of the thesis so far, and present them in such a way that the empirical part of the research might sit comfortably amongst them. Acknowledging that the social research cannot be carried out in isolation from society or the biography of the researcher, I have tried to locate the project within the wider contexts of the Hokianga and my own circumstances. I have outlined the reasons for undertaking the evaluation study, which was primarily to do with the desire to produce something useful for all those involved in the research. Despite its limitations, a community study approach has an important symbolic role, which should not be underestimated, because the ability of local groups to refer to their own studies might be vital in persuading those responsible for health and social services to at least consider their needs (Blakemore and Boneham 1994: 12) In summary, therefore, influenced by specific theoretical literatures, I hope to interpret some of the health effects of social and/or cultural marginalisation in the Hokianga region of New Zealand. My aim is to evoke ideas rather than try and represent 'reality', in order to avoid the pitfalls of representation, and to maintain an awareness of the political and ethical implications of my work. In doing so, I concentrate on three perspectives. In Chapter 6 I focus on broad discourses of rurality, 'race' and illness. In

Chapter 7, I narrow the focus and explore a range of issues that are specifically connected with home help, for example, the *whanau*/family policy, privacy and dignity, gardening and employment. In Chapter 8 I focus on an even narrower set of ideas: those of the body and embodiment. By using home help as a vehicle, I am therefore able to explore a variety of issues that connect in with home help, but are much wider than it, - issues that also connect in with discourses of otherness, difference and embodiment.

CHAPTER 5. METHODS AND INTERPRETIVE STRATEGIES.

5.1. INTRODUCTION.

Why bother to study health? Firstly, I would argue, it is an important topic to study in order to establish disease aetiology. This will increase our understanding of why and how people get sick. Secondly, in terms of policy planning we need to know what services people require and where. Thirdly, there are political reasons for taking health issues seriously - as an issue of public concern, any politician who deems health topics unworthy of attention simply doesn't get votes. Regardless of what definitions of health are used, within health research, there are two broad categories of health measures: outcomes and processes. Outcome measures focus on a readily identifiable end-point such as the disease process or illness state in terms of morbidity and mortality. Process measures focus on throughputs indirectly linked to the disease process or illness state such as service utilization, provision, expenditure, or, 'indicators of well being', for example GNP, housing or domestic violence. But statistical analyses of mortality and morbidity, and the even rhetoric of health promotion leave little room in for theoretical concerns such as power relations, or capitalism as a redistributive mechanism. Part of the problem is that politically speaking health care is a short term, not long term planning affair. The result of this is that health research is most often thought about and operationalized in the short term only.

Like the subject it studies, much health research is heavily influenced by modernistic scientific methods. Batchelor and Briggs (1994: 952) point out that '...one particular aspect of much social and some medical research...is concerns

over the extent to which it is perceived by the research community at large as scientific. As a consequence of these concerns there are pressures within the social sciences to strive towards methodological traditions legitimated by positivism'. The implications of a positivist tradition in much health research means that a potentially rich data source is not being adequately explored. Qualitative research may add much to our depth of knowledge and understanding of health situations by probing sources such as narrative and oral history. As yet though, it remains a marginalized methodology, despite calls to challenge this (Black 1994; Mattingly and Garro 1994).

The previous chapter outlines the rationale and the history behind undertaking this particular project. This chapter documents the methods used to conduct the study, and the grounds for choosing such an approach. Because I was hoping to do different things with the information gathered, the selected methods had to be quite flexible. This was one important reason for choosing qualitative techniques. A questionnaire could have given me answers to only one set of questions - or have been too brief to answer either set of questions in detail, or have been too long and complicated. In a qualitative analysis, results take the form of words rather than numbers. With a qualitative approach, I could gather material for the evaluation for Hokianga Health Enterprise Trust (HHET), as well as material for my own interests, for example, information on the cultural aspects of health. Moreover, approaching the fieldwork in this way enabled me to uphold my own personal commitments to providing local, *useful* research, as well as combining certain academic theoretical topics (postcolonialism, postmodernism, poststructuralism, the body) with not only a medical geography, but also the realities of everyday life, including the experiences of illness and disability.

Questions to be addressed.

These fall into two broad categories. First, the questions associated with the evaluation part of the research. The evaluation must ask specific and feasible questions in an effort to understand, for example, how users perceive and evaluate Home Support Services (HSS); how the social and cultural context influences HSS; to investigate causal processes; too provide information that can be used to improve the system; and lastly, to provide information to decision makers. The research and evaluation should include questions about the following: the external environment of the organisation; the internal environment of the organisation; the Home Support service users; the Home Support Service environment and staff; the management and operational environment; patterns of utilisation; organisational impacts; and social impacts. The sorts of questions that may be investigated include: What is happening here? How is it happening? How has it come to happen in that particular way? What do the people involved think is happening? How are these people responding to what is happening? Why are these people responding in that way? How can home help services be improved? Do they need to be improved?

Second, I am interested in how these questions might enable me to extend understandings of the socio-cultural dimensions of health. In analysing the constructions and interpretations of different discourses of health I hope to examine the material linkages between social, political and economic relations and health. This will allow me to analyse the consequences of hegemonic constructions of health in two ways (i) how they affect marginalised groups; and (ii) how they affect marginalised representations of the body.

5.2. QUALITATIVE TECHNIQUES.

Research methodology in a study such as this should be

“sensitive and flexible...embrac[ing] the views and opinions of ordinary people in their own terms. It also requires that the context of people’s lives be incorporated, so that their views do not become divorced from the meanings in which they were originally situated”
Donovan (1988: 182).

It seems to me that unlike quantitative ones, qualitative methods are flexible enough to integrate the disparate theoretical issues I am interested in with empirical social and medical ones. They are helpful in understanding the meaning and context of what is being studied, as well as the particular events and processes that make up those phenomena over time, in real life settings. This is not to render quantitative methods useless, but that for my purposes, qualitative methods are more appropriate. In order to try and understand the ways in which others construe, conceptualise, and make sense of what is happening in a particular situation, a number of techniques can be used. Observations, interviews, documents, transcripts, open-ended interviews and conversations can be used to give a detailed descriptive and analytic account of what is going on (Atkinson 1990; Berg 1989; Burgess 1980; Cook and Crang 1995; Eyles and Smith 1988; Hammersley 1991; Hammersley and Atkinson 1995). Use of these techniques require somewhat skilful and systematic approaches to questioning participants, ranging from informal conversations through to interviews with a specific, tightly controlled agenda.

Open-ended interviews are useful in eliciting respondents’ views and experiences in their own terms, rather than collecting data that are simply a

choice among pre-established response categories, as in the case of a questionnaire. Although I had an idea of what topics should be covered in the interviews, (indeed, this was negotiated with the Chief Executive Officer of Hokianga Health Enterprise Trust,) I used this open-ended strategy in order to gain maximum information without making the interview situation overly contrived (Kaplan and Maxwell 1994: 56). In this way, I was not bound to a rigid format or set of questions and therefore had the opportunity to elaborate on specific points. Furthermore, using this method meant that participants had more control over what they chose to tell or not tell me. This important point is elaborated in Section 5.8.

Ethnographies and narrative.

'Classical' Anthropology is all about studying 'the 'exotic' over time, using techniques such as ethnography and participant observation (see for example Evans-Pritchard 1940; Fabian 1983; Malinowski 1922; Mead 1949; Rabinow 1977; Shostak 1981). Ethnography is a multi-method approach that includes observation, participation, archival analysis, and interviewing (Reinharz 1992: 46; Roman 1992). It is neither subjective or objective, rather it is interpretive (Agar 1986: 19; Atkinson 1992). Recent calls for a 'critical ethnography', (Quartz 1992: 497) can help to inform how we construct and think about common concerns, by providing empirical evidence that suggests that social issues (including medical ones) are essentially the sites of cultural politics. Although Quartz acknowledges the difficulties of defining a critical ethnography, he highlights five themes found in its discursive practices: society, culture, history, knowledge and values (Quartz 1992: 450). He further argues that

whereas 'traditional ethnography' considers the ethnographic project as complete in itself, a critical ethnography is an aspect of critical theory which '...must eventually be completed in political and social action' (p467). I would argue that any attempt to produce an adequate ethnography should be situated in its wider social context as well as draw out any implications for social change. This conviction allows me to situate this project within the domain of 'critical ethnography'. Drawing on these ideas, I hope to produce a piece of work that not only allows for social change at a local level, but also contributes to the wider societal and theoretical debates outlined in Chapters 1, 2 and 3.

Ethnographies are composed of words, accounts, stories or narratives. The narratives of ethnography are a cognitive process that organise human experiences into temporally meaningful episodes, looking for particular connections between events (Polkinghouse 1988: 17). Narrative can thus be seen as a way of translating knowing into a sequenced telling. Although the oral is often associated with non-educated/non-elite or 'primitive' peoples, I do not think of narrative in this way at all, but simply as the most common form of communication between human beings. Explanation by means of narrative is contextually related and is therefore different in form from formal science explanation (Polkinghouse 1988: 21). Taking narratives seriously means taking local knowledge seriously (Gourley 1993: 364) and I am primarily interested in the narratives of every day life, in this case, of Home Support Services in the Hokianga.

Situated within a 'critical ethnographic' tradition, the narratives I have collected can be seen as part of a wider (health) discourse that is inseparable

from social and political matters. Narratives are temporally and spatially situated; therefore they need to be situated in the social conditions under which they emerged. Narratives display cultural particulars (Silverman 1995: 114) and they are further complicated by those particulars for example, historical details, ethnicity or gender. The kinds of stories we tell, as well as their subject matter, reflect cultural presuppositions and values (Toolan 1988: 164). Social conditions determine the properties of discourse (Fairclough 1989: 19) and the case of Home Support Services in the Hokianga is no exception. For example:

“...because people here don't get meals on wheels, they don't get the hospice nurse, everything is dependent on the community. The resources have to come from the community. And that's why the home help service is so important to us...they haven't been able to close [the health system] down. They've closed the post office they've closed the bank - and the Hokianga tends to carry on. This is *our* health system.”

Narratives can be many things, written, spoken or signed, for example, biographies, novels, histories - even government policies; they are produced and used in different ways to achieve different ends. They can be seen as a way of translating knowing into telling, and I am primarily interested in the narratives of every day life, in this case, of home help. These narratives are part of a wider (health) discourse that is inseparable from social and political matters. I am therefore also interested in the discourse of home help from a policy perspective. Thus in this instance, the term narrative is used for both written official policy documentation, and shared conversations with those who have direct experience of home help. Social conditions determine the properties of discourse (Fairclough 1989: 19) and the case of home help in the Hokianga is no exception. Narratives are produced and used in different ways to achieve different ends. They are constantly changing: they are continually contested, rewritten and

retold. In the context of this research, I have been influenced by the idea that narratives have potential political influence, in that they have the power to initiate change. Moreover, using narrative as a way of interrogating the issues at hand enables a community to voice and take possession of their concerns.

Narrative is a structured sequence of events in time, a cognitive process that organises human experiences into temporally meaningful episodes (Polkinghouse 1988: 17). Yet at both social and individual levels, narrative does not originate externally, nor does it impose a story line on what was previously a mass of unrelated facts. It is actually inherent in the process in the first place (Carr 1986: 177, cited in Langsdorf 1993: 40). The narrative mode looks for particular connections between events, and explanation by means of narrative is contextually related. It is therefore different in form from formal science explanation (Polkinghouse 1988: 17-21). Langsdorf has identified three distinct levels of narrative organization. (i) as intrinsic to lived experience; (ii) as the structure of oral discourse; (iii) as specific to written discourse (1993: 39). He argues that the differences between oral and written narrative structure are rarely discussed, and that the possibility of a distinct dimension of lived experience has hardly been noticed (*ibid.*). In response to Langsdorf's criticisms, and as part of the evaluation of the home help service, I have examined both oral and written narratives, as well as lived experiences.

I am therefore influenced by ethnographic approaches, and particularly in the use of narratives as alternative ways of knowing. This is reflected throughout the project and stems from my belief that medical geographies need to be more attentive to 'geographies from below' as well as the fact that a contextualised

approach demands a qualitative approach. In addition, thinking through social rather than biomedical issues of health moves the analysis away from traditional numerical analyses of biomedicine, towards a contextualised understanding of the lived realities of illness and disability. Because of intertextuality and lack of closure, texts (including narratives) should not be seen as self-standing entities, but as always being defined and referenced in terms of other texts. Lack of closure is not necessarily a failing of the project, rather it comes with the realisation that these narratives are constantly changing, continually contested, rewritten and retold. In this way, links with theoretical issues, particularly poststructuralist lines of thought can be strengthened and made more explicit; I shall follow this comment up in Section 5.4.

Participant observation and fieldnotes.

Many studies of narrative are based on taking the notion of talking-as-text as the point of departure. I would argue that there are also other forms of text to consider when dealing with narrative. They are closely linked with the previous discussion in Chapter 2 on the body and embodiment and require interpretive techniques such as observation (Spradley 1979). Tales and stories are not just spoken: they are often acted in the sense that the teller's skills may considerably enhance a story and its interpretations. Analysing solely words assumes they constitute the essence of the story. This misses the need to see other language (body) as a contextualised constituent part of the text. Thus body language, gesture, and facial expressions should be seen as integral to the verbal text and its meaning, not as mere extras. I see the whole 'performance' of narrative as part of the analysis, not just the transcribed words, hence the

importance of participant observation and fieldnotes. For example, I spoke with a home help client who was very frustrated with his situation. Confined to a wheelchair and with pulmonary disease, he squirmed and wheezed all through the interview. The more agitated he became, the more he squirmed and wheezed. Yet these activities remain hidden in the transcripts, because they do not lend themselves to easy transcription. The transcript reads as a fairly calm, straightforward conversation, yet I know that the man was becoming increasingly distressed as the interview progressed, and this is reflected in the notes I wrote after the interview. On a different level, I was constantly reminded that somebody language is a product of cultural and social conditions. For example, it is customary for Maori not to look people in the eye when speaking as this is considered bad manners. I found this very difficult to deal with, because I am from a culture that assumes the opposite. I must have offended many people, even though I tried really hard not to do it.

I am using the term participant observation (PO) in loose terms to describe my own involvement in the research process. Conducting face-to-face interviews with participants, and living in the area in which I was working, were two important elements of my participation in the study. Living in the area gave me sustained immersion in local life, which I hoped would enhance my understandings of the Hokianga life. Face-to-face interviews meant I could see how people were reacting in terms of body language as well as listen to their stories. Taking this kind of approach implicates me as (part of) the 'audience' that received the 'performance' of those narratives, and this links back neatly to the discussion on positionality in Chapter 4. My presence, interview style and

personality will have influenced my (re)actions and reception of narratives, and this in turn will have altered the performance in various ways.

Fieldnotes consist of relatively concrete descriptions of social processes and their contexts (Hammersley and Atkinson 1995: 175). Their main purpose is to identify and develop what seem to be the most appropriate categories for coding and categorising the data. As the interviews progressed, the subject matter of my fieldnotes changed as new issues arose, or what had previously been seen as more or less irrelevant took on heightened importance. An illustration can clarify this. At first, diary entries consisted largely of information regarding Home Support Services in the Hokianga. Once I understood how they operated, I could concentrate on details rather than the big picture. Thus the entry on 16th November, 1995, dealt with general features of home help in the Hokianga:

“About 60 receive Home Support Services, - chronic disability, mostly age related, medical problems, physical disability, mental disability’. The 29th November, 1995 recorded more general information about the Hokianga, in this case, population profiles of the region: ‘The population is a fairly young one, so childhood/young adult issues figure more than elderly ones.’ (Diary 1, 29.11.95.)

As time went on, entries became more specific, particularly with reference to ethnic and cultural differences. For example, the entry for the 8th May 1996 reads:

“We lose about thirty sheep a year and we know its the blacks who do it - we just can’t prove it.” (Diary 2,. 8.5.96)

“Sarah explained how all body parts, whether arms, legs, ovaries or afterbirths are given back to the person from which they came. Then they are buried. At her church, one area is dedicated for their afterbirths. Every time an afterbirth is buried, a bush is planted

over it. That way others can know another afterbirth has been buried. The bush is sacred. Families tend to have 'patches'. For instance, Sarah's daughters would bury their kids' afterbirths near the bushes that were planted for Sarah and themselves." Diary 2, 25.5.96)

Thus my fieldnotes became more concrete and detailed over time. This combination of interviews, PO and fieldnotes have given me ample data from which to construct an account of Home Support Services in the Hokianga. From the same data I have also been able to consider the culturally diverse experiences of embodiment, health and disability, and Maori-Pakeha culture in the Hokianga, as well as more generally in New Zealand. The data has been used in this way as a point of departure for thinking through what this might mean for a theoretically enlivened medical geography.

5.3. EVALUATION STUDIES.

I outline the reasons for doing an evaluation study in Chapter 5. This demanded flexible research procedures, and in large part this influenced my choice of qualitative methods for the project. However, knowing I was going to do a qualitative evaluation was not enough. I had to know *how* to do it. As I had not conducted a formal evaluation study before, I first needed to familiarise myself with the different approaches in current practice. Like many other fields of research, there are two main ways of going about an evaluative study: quantitative and qualitative. Although these two methods are often seen in opposition to each other, it is more useful and productive to see them as complementary to each other. The logic of good quantitative and good qualitative research designs do not fundamentally differ. One technique is not superior to the other, it simply depends on the types of questions you are asking. Quantitative

methods concentrate on statistical analyses and usually have questionnaire or survey type formats. Although they can generate a lot of numerical data and look very impressive, they often require sophisticated analytic techniques, and the tightly structured questionnaire format does not allow people to elaborate on what they see as important to the research. This means that there is a possibility of ending up with research results that address what the *researchers* were interested in, but not the respondents. The outcome of this will be that the research will be of little benefit to the population whom it was designed to benefit. As Evans et al argue, “Evaluative research has historically been ineffective in devising measures that accurately measure outcomes of service inputs in ways that are also meaningful to the lives of service users” (1990: 220). In contrast, this study takes the concerns of service users seriously, so that the results will be useful to both clients as well as staff.

An evaluation identifies “the extent to which needs are met by the service and to review activities in the light of changing needs” (Simpkins 1994: 26). Hames (1990: 169) describes the four main reasons for undertaking an evaluation study as follows: (i) to ensure that a service is doing what clients/families want it to do; (ii) that a service is doing what it says it is doing and what people paying for it think it is doing; (iii) to see if a service is ‘better’ than another service (in large part a moral judgement); and (iv) to establish whether the service is ‘good value for money’. There are many different models of evaluating services, and there is no one correct way. They should, however, all be framed in terms of their goals, decisions, issues, problems, values, systems and comparisons (Patton 1986: 65). For example, what is the purpose of the evaluation? How will the information be used? What will we know after the evaluation that we don’t know

now? What can we do after the evaluation that we can't do now for lack of information? The sorts of questions asked in an evaluation will determine the methods used to collect and interpret data. Specific methodological approaches will therefore be guided by the sorts of questions asked.

Clearly, different types of questions will lend themselves to different types of analysis. As the term suggests, quantitative analysis concentrates on measuring and counting the phenomena under study. Summative questions lend themselves to a quantitative framework for analysis, because the answers to the questions are relatively easy to measure. Examples of summative questions could include: Has the programme been effective? Should it be continued? Is it worthwhile? Did the programme cause the desired outcomes? The two most common types of summative analyses are outcome/impact analysis and cost-benefit analysis. Outcome/impact analysis tries to determine the difference between the courses of action being considered (usually the difference between the current mix of services) and what would happen if a new course of action were undertaken. It asks questions such as: What are the direct and indirect programme effects? Cost-benefit analysis assesses whether a programme had impacts that were sufficiently large to justify its costs. It asks the question: What is the relationship between programme costs and programme outcomes (benefits) expressed in dollars, pounds or whatever?

However, when an evaluator wishes to study issues that are not easily partitioned into discrete entities, or to examine the dynamics of a process, rather than its static characteristics, qualitative methods are more useful than solely quantitative ones (Kaplan and Maxwell 1994: 45-46). The goal of a qualitative

evaluation is to try and understand the situation from the participant's point of view as well as the institutional context - these goals are largely lost when textual data are quantified. From an evaluation viewpoint, it is often difficult to formulate meaningful hypotheses in advance, because the evaluator does not know enough about the participants' situations and perspectives. This means the evaluator must use an inductive approach, developing and testing hypotheses during the process of data collection and analysis. How and why questions then become progressively narrowed and more detailed as the evaluation proceeds. Qualitative evaluations are helpful in understanding meaning and context of the phenomena studied and the particular events and processes that make up these phenomena over time, in real life settings. As such, they tend to be in-depth case studies of particular systems that analyse processes rather than static (and therefore more easily quantifiable) outcomes.

In these cases, the questions asked tend to be formative ones. Formative questions are much harder to quantify, therefore they tend to be more descriptive, and are focused on a specific context. Because of the context-specific nature of formative evaluations, there is no attempt to generalise findings beyond the setting which is being evaluated. Formative frameworks consider the strengths and weaknesses of a programme, and asks questions such as: Can the programme be improved? What is working well and what isn't working so well? What are the reactions of clients, staff and others to the programme? What are the things people experience that make this programme what it is? What are their perceptions about what should be changed? How are clients brought into the programme? What is the nature of staff-client interactions?

Process evaluations qualitatively examine the strengths and weaknesses of day-to-day operations within the programme and ask questions of a formative nature. Process evaluations describe the programme and the general environment in which it operates, addressing questions of who is served, what services are provided, how much it costs, and whether the programme could be replicated if so desired. Process data allows formative questions to be asked. Formative evaluations are aimed at programme improvement and therefore often rely heavily on process data. By describing the dynamics of the programme processes, it is possible to isolate critical elements that have contributed to programme successes and failures (Patton 1986: 96). There are several process evaluation models currently in use. These include goals-based and goal-free evaluations; responsive approaches; connoisseurship studies; and utilisation-focused evaluations (Patton 1986: 15). They all emphasise the contextual nature of their approach, the dynamism of processes rather than outcomes, and the importance of face to face contact with participants. As such, their stylistic differences tend to be of degree rather than kind.

I have already suggested that the way in which an evaluation is undertaken depends what you want to find out. For instance, North Health (the Regional Health Authority for Auckland and everywhere north of Auckland), measures the performance of Home Support Services in terms of accessibility, acceptability, effectiveness, safety and efficiency (RHA Audit, 1995). The questions they asked were to be answered on a yes/no basis. This is because they were interested in finding out whether certain standards were being upheld, for example, whether written policies are in place, and whether cultural issues are safeguarded. Clearly, these types of questions lean towards a yes/no approach

rather than a more qualitative, descriptive approach. In contrast, this study takes a different but complementary approach to the RHA Audit. Opinions and perceptions are hard to measure - they do not fit easily into yes/no categories. Yes/no answers often decontextualise a lot of information, because they do not allow for full explanations of why a situation is the way it is. Because this study depends on people's perceptions and opinions, methods must be found that allow full descriptions of the situation. Therefore, opinions and perceptions will be presented as excerpts of conversations and interviews, in order to give more contextualised answers. By doing this, the dynamics of the every day running of Home Support Services was be explored.

A primary assumption of this study was that understanding would emerge most meaningfully from an analysis of open ended detailed descriptive data collected through direct contact with the programme and its participants. This meant that qualitative methods appeared more appropriate than quantitative ones, because they are more effective for gathering people's opinions and perceptions. The research was therefore designed as a qualitative study, investigating people's opinions of Home Support Services in the Hokianga. The intention was to collect stories and opinions of how the service was doing, to search for underlying patterns and themes in those stories and then to present them in a written report. This report has since been presented to HHET.

5.4. THEORETICAL LITERATURES.

Although the main thrust of this project was to conduct an evaluation of Home Support Services for Hokianga Health Enterprise Trust (outlined in

Chapter 4), I also hoped to gather information regarding my broader theoretical/academic interests. In Chapter 2, I have already sketched out the main theoretical influences of this study. The purpose of this section is to try and link those theoretical literatures with the practicalities of doing a research project of this nature.

Glaser and Strauss (1967) emphasise the advantages of developing theory through systematic data collection rather than 'armchair theorising'. This they refer to as 'grounded theory'. Rather than having a pre-determined collection of theories from which to draw, or an *a priori* hypothesis to test, they see theory development as best achieved through making sense of the data one has collected. However, I would suggest that the relationship between theory and data collection is much more complex and subtle than this, and that one can be (and should be) familiar with broad theoretical frameworks before entering 'the field', but that they should be subject to modification throughout the research process as appropriate (Crang 1992). Thus rather than seeing theory and practice as two separate parts of the research process, I see them as necessarily and inextricably intertwined.

The theoretical frameworks informing this project, have already been introduced in Chapter 2. In particular, I am interested in examining post-modern and poststructuralist lines of thought and trying to work out whether they can be useful to this study as well as others. Broadly speaking, I am drawing on postmodern notions of 'Otherness' and exploring their geographies in terms of social and cultural marginalisation. Why is the Hokianga viewed as a poor, Maori area? How did that view come into existence? How is it perpetuated?

What are the implications of this for health issues?. Considering the mechanisms behind this process of 'Othering' could enhance our understanding of how these processes operate within society. Another facet of postmodernism pays attention to the importance of polyvocality and political empowerment (Crang 1992; Ley 1994: 466). These two ideas resonate well with my convictions about doing research that local people are interested in and can use. A large part of this project is made up of different voices, including my own, and because people in the Hokianga have had a stake in this project, I think they are likely to follow-up and make use of the results.

From poststructuralism I am also borrowing concepts of discourse. From this perspective, discourses (and by extension texts, and narratives as sub-sets of discourses) can only be understood in the contexts of other related texts. Following Mishler (1986) I would argue that interviews can also be seen as a type of discourse. This interview discourse is simultaneously structured by both interviewer and interviewee, and situated within wider societal relations and discourses. While few studies of oral tradition and narrative label themselves as 'poststructuralist', recent work has quite often made use of poststructuralist themes such as intertextuality, of multiple rather than single meanings, of rejecting a search for objectively-fixed laws and generally questioning fixed models of text and meaning (Hammersley and Atkinson 1995: 13-16; Finnegan 1992; Gubrium and Silverman 1989; see also Chapter 3). These themes are also apparent in this study.

Often affiliated stylistically with postmodernism (Jackson 1994: 465), postcolonial ideas are also apparent in this project. The links with

postmodernism can be seen most clearly through the postcolonial trend towards polyglossia (Mishra and Hodge 1991: 288). The emphasis on literary criticism and discourse also allies this perspective with poststructuralism. There is a call for marginalised, oppressed and dominated voices to be heard but without distortion. This is extremely difficult to achieve, and I would make no such claims about this particular study. Whilst much of the postcolonial literature remains abstract and theoretical, it is real people who have experienced the actualities of colonial and postcolonial conditions. Franz Fanon described this as 'the fact of blackness' where black bodies are seen as evil, hated and ugly. It is thus bodies on which the experiences of colonialism and postcolonialism (and health and ethnicity) are inscribed. The rise of postcolonial and poststructural ideas has profoundly influenced how bodies can be conceptualised. In the same way that texts and discourses are seen as unstable, poststructuralists also see both subjectivity and the body as being in a constant state of flux; a site of conflict and contradictions, and therefore political change. How people think about their bodies is influenced by historical, geographical, political and cultural circumstances. This argument is further developed in the discussion on embodiment in Chapter 7. In this project, an awareness of the theoretical dimensions of the body is necessary, firstly because this is where the discourses of health and ethnicity (amongst other things) collide, and secondly because in reality, there are marked cultural differences in how people comprehend their own corporeality.

5.5. RESEARCH DESIGN.

The project had to be designed with two broad aims in mind. On the one hand, I needed a research design that would enable me to gather information to evaluate Home Support Services. On the other, I wanted to also explore the broader social and cultural meanings and experiences of illness and corporeality, as well as the links between marginalisation, health and social life. The flexibility required for such an undertaking led me to devise a topic guideline that contained the necessary questions for the evaluation, but that also allowed me to follow up other leads perhaps more pertinent to my second line of enquiry. This meant that on paper, the topic guidelines concentrated on the evaluation part of the project. In practice, however, there were ample opportunities to ask unscheduled questions and follow a more unstructured approach, so that different leads could be followed up. Although the next section focuses on the research design of the formal evaluation, the comments about my unstructured approach and unscheduled questions should be borne in mind.

The first part of formulating the research design was to define carefully the questions that were to be asked from the point of view of evaluation. These varied, depending on whether one was addressing clients or staff involved in the programme. (The programme and its participants have already been outlined in Chapter 4). Rather than having a questionnaire from which to work, the research questions were incorporated into 'topic guidelines' which were of a deliberately broad nature (See Appendix 4). This was done so that participants might have the opportunity to speak freely about issues that concerned them in a sequence they chose. Once the topic guidelines had been approved by the Principal Nurses and

the Chief Executive Officer (CEO) of Hauora Hokianga, the research could begin. A letter was sent out to everybody receiving Home Support Services, or working in the capacity of care giver or Community Health Nurse. This letter explained the purpose of the evaluation and invited them to take part. It also included a summary of who I was, where I was from, and why I was doing the project (See Appendix 3). Everybody was offered the services of an interpreter - in the event only two actually accepted this offer. Even so, a highly respected member of the Maori community, Sarah, joined me on visits to Maori homes. This was not only for translation purposes, but also to help reassure people not used to the presence of Pakeha strangers in their home. Without her input, this study would not have been possible - and doubtless, some of the conversations would have been very different, had they occurred at all.

In total, 117 letters of invitation were mailed to clients, staff and Community Health Nurses. 5 answers were sent back declining the opportunity to take part, and 43 initial replies were received agreeing to participate. (5 Community Health Nurses, 24 clients and 14 care givers.) Those who'd accepted the invitation to participate were telephoned, or written to, to arrange a convenient time for me to visit. A deliberate strategy was to conduct the interviews in winter time, when less seasonal work would be available and people have more free time. I also thought it would be tactful to wait for Easter to come and go. My diary entry for April 1st 1996 reads:

“Easter is a busy time usually. There are many unveilings. Once a person has been dead for at least a year, the [head]stone is unveiled. Venus [a nurse at the hospital] says that traditionally, if a

woman's husband has died, once the headstone has been unveiled, then she is free to find herself a new husband"¹.

However, a problem emerged whilst I was setting up the interviews. Approximately 70% of respondents to my initial request were Pakeha, yet Pakeha made up only 30% of the population in the Hokianga. This meant that the group of people who were willing to be interviewed were not representative of the area as a whole. Had I not been doing the evaluation for Hokianga Health Enterprise Trust, this might not have been an issue, but I was, and I felt that the group who agreed to participate should reflect the ethnic composition of the total client group. This meant I needed to encourage more Maori to join in. I sought advice from Sarah, who would be accompanying me on visits to Maori homes. She suggested I gave her the list of Maori who had not answered and she would phone them up. They would therefore be approached by someone they knew and trusted and might be more willing to take part. This strategy worked well. The outcome was that 70 interviews were arranged that reflected the ethnic composition of those receiving Home Support Services as well as the wider

¹The *hura kohatu* or unveiling ceremony is one of many types of *hui* (social gatherings) organised by Maori and is a special occasion for remembering the dead. Several families belonging to a particular area or tribal grouping will assist with the memorial gathering. One of the customs of the *hura kohatu* is for members of close kin to go before sunrise, while it is still dark, to cover the headstone with a cloth. It is believed that the spirits of those who have died, and the gods, are present in the cemetery and are able to influence the living in some way. When the unveiling service is over, the people return from the cemetery and take part in a special feast or *hakari*. Unveiling services are very much like funerals, but usually many headstones are unveiled on the same day, and in such instances many families will co-operate with one another to make it a successful and memorable event. Often, months of planning go into these *hui* and notice of an unveiling is sent out to family, relatives, friends a few months in advance. (Barlow 1991: 30)

population of the Hokianga. These points have already been elaborated in Chapter 4.

As the study progressed, it became apparent that in terms of ethnicity, these figures were far from representative of the total people involved with Home Support Services, or with the Hokianga population as a whole. For example, the response rate for Maori clients was 30% whereas the response rate for Pakeha clients was 60%. The response rate for Maori care givers was 26%; for Pakeha care givers it was 71%. (All the CHNs are Pakeha - itself an interesting point, so this was not such an issue in their case.) In an attempt to make the study more representative (important from the Regional Health Authority's and HHET's perspective,) I telephoned all the remaining Maori clients and care givers who had not replied to my original invitation. Fortunately, many agreed to take part. In the end, 66% of total clients were interviewed, (64% of Maori clients and 68% of Pakeha clients²). Similar to the Hokianga population as a whole, of the total, there are 2.2 Maori clients for every Pakeha one. The interview ratios were 1.75 Maori clients interviewed for every Pakeha client. In sum, 38 clients were interviewed, 31 women (19 Maori and 12 Pakeha) and 7 men (5 Maori, 1 Cook Islander and 1 Pakeha). 27 care givers participated in the study, 24 women (15 Maori, 1 Cook Islander and 11 Pakeha) and 3 men (2 Maori and 1 Pakeha). These numbers reflected both the total Hokianga population as well as the sub-population of people involved with Home Support Services. Thus the study could withstand any criticisms about questions of representativeness on ethnicity

²These figures have been adjusted for the 4 deaths (all Maori) that occurred during the study.

grounds. However, it was impossible to encourage enough men to participate in the project, and so it could be criticised for over representing women and underrepresenting men.

5.6. STUDY AIMS AND OBJECTIVES.

From my own perspective, this study had two broad aims. Firstly, to provide socially useful research, and secondly, to explore what a theoretically infused medical geography might look like. From HHET's perspective, the study aim was to give them enough information upon which they could act. This meant that I was trying to gather information that would allow me to do two different things. But my emphasis had to be on the practical evaluation rather than the theoretical substance, for two reasons. Firstly, I owed it to HHET, particularly to the CEO to make a good job of the evaluation. After all, I was allowed access to their records and clients, provided with staff and computer backup, they paid for all the printing and postage costs, and gave me free accommodation, as well as supplying me with a hospital car - even the petrol was paid for. I really didn't want to let them down. The second reason for my emphasis on the practical evaluation rather than the theoretical side was that the people I was talking with could understand the reasons behind the evaluation. I suspect trying to explain my theoretical influences of postmodernity, postcolonialism and the body would have left people both cold and hostile to the project. Participants knew I was a visiting student and that I was gathering data for a PhD, but I minimised the emphasis on theory and academe because I thought it too elitist (particularly given the social circumstances of the Hokianga) and most people just weren't interested anyway. Thus although there were two broadly distinct motives for the

study, I accentuated the practical issues over the theoretical ones. Taking this view meant I designed the evaluation with a view to talking mainly about home help issues, but hopefully accumulating any additional (theoretically relevant) data en route. This meant that I drew on *very* disparate literatures, from the practical fields of evaluation, as well diverse social-theoretical, medical and geographical literatures. From the research practicalities point of view, the emphasis of the practical over the theoretical has had significant implications for the study design. What follows is an account of how the aims and objectives for the evaluation were formulated, supplemented by an assessment of how they ultimately contributed to the actual design and process of the research.

Any evaluation must be preceded by a clear statement of study aims and objectives. The overall aim of this study was to produce accurate, credible results that could be used by decision makers and practitioners involved in Home Support Services. The study also had two subsidiary aims:

- 1) to identify the extent to which needs were being met by the service, and
- 2) to uncover the achievements and shortfalls in services, from the points of view of both clients and staff.

These two aims are important because they are powerful tools in supporting a case for resources. The objectives are the goals that need to be reached in order to achieve the aims. They are:

- 1) to identify key areas of concern, so that services might be directed towards meeting these,
- 2) to provide basic qualitative data about areas of services people most need at present,
- 3) to provide an indication of the satisfaction with current service provision from both the client and staff perspective (After Simpkins 1994: 33).

Once the aims and objectives, were established, I had to define carefully exactly what was being evaluated. What exactly does Home Support Services in the Hokianga mean? What does it entail? Bearing this in mind would allow me to ensure that the research was specific to the Home Support Services rather than something outside its mandate. I have already described Hokianga's Home Support Services in detail, in Chapter 4. But in addition to the formal evaluation, I was also keen to gather material for my own interests - about the lived experiences of illness and corporeality. This side of the study did not figure at all in the evaluation report I wrote for HHET, because they were not concerned with these matters. But where I could, I pursued relevant lines of enquiry with participants, in order to try and get at least some clues in how people perceived these matters.

5.7. ADVANTAGES AND DISADVANTAGES OF THE METHODOLOGY.

The major advantage of the method used in this study is its flexibility. Although a topic guideline was used, the study was designed in a way that would

allow participants, not the researcher to voice what they saw as the important points. Moreover, the emphasis on talk and stories meant that they could converse comfortably in everyday language. This meant that no two interviews were identical either in form or content. By conducting the research in this way, (that is, in-depth conversations) it became possible to understand the issues from the participant's point of view. As already pointed out in Section 5.3, this can be seen as a useful complement to the Regional Health Authority Audit, which does not take staff or client views into account.

By not having pre-determined categories in which to place data, themes and patterns emerged as the interviews took place. The role of companionship for example, came up repeatedly, as did the question of allowing family members to be home helpers. The flexibility of the interview structure meant that certain points brought up in the conversations, such as those above, could be elaborated on in a way that would have been impossible in a closed-question survey. The research therefore had more relevance for the contributors because they had a chance to contextualise and explain their point of view, in language that was familiar to them. Often this included slang terms, occasionally swearing and, of course, Maori. People were encouraged to speak how they normally speak, so that the interview was less of a formal situation. For those who spoke Maori, (mostly the older Maori clients) the conversation proceeded predominantly in Maori. Where appropriate, Sarah (the interpreter) suggested speaking in English so that I (as a non-Maori speaker) might understand parts of the conversation. The reassurance gained by having a *te Reo* (Maori language) speaker present must not be underestimated. Not only is it a person's right (New Zealand has two official languages, Maori and English), it also created a safer environment for

people to speak in. Furthermore, there were some topics of conversation that would be considered unseemly or embarrassing, perhaps even rude to be spoken about in English, but could be accommodated in Maori in a much more fitting manner. For example, conversations about personal clothes washing, or personal hygiene were much more acceptable in Maori, particularly to the older participants. For them, these sorts of things could not be adequately discussed in English without being considered crude or discourteous. These conversations were later summarised for the researcher by the interpreter in private (usually in the car on the way home). In privacy, they could be freely discussed and analysed. This was certainly a positive learning experience for me as an outside investigator, particularly with reference to cultural norms and practices. The diary entry for the 31st May, 1996 illustrates this point well:

“Sarah told me the other day she has never practised her *te Reo* (language) so much. When she was a cleaner at the hospital, a (Maori) lady was in bed with abdominal pain. Nobody could work it out. One day she said to Sarah, “If I could just have a good crap, I’d be fine!” So Sarah was able to tell the doctors what the cause of the abdominal pain was. But the lady would never have said that in English as she was too embarrassed, nor did she know the English word for constipation.” (Diary 2, 31.5.96)

There are, however, several criticisms that can be made of this methodology. In my opinion the most problematic is the sheer numbers of participants involved. A qualitative study of this sort ideally would have in-depth interviews with perhaps up to twenty people. This study has escalated out of all proportion in the desire to maintain a balanced representation between clients and care givers, and their differing ethnicities. This means there was not enough time to fully transcribe the recorded interviews. They have been partially transcribed, but possibly lose some of their context when they have to be used in

this state. On the other hand, 70 interviews is far too many for a decent, comprehensive qualitative analysis, even if there had been time to fully transcribe them.

From a quantitative point of view, the numbers in the sample are fairly small - 38 clients, 27 home helps and 5 CHNs. Because these groups were analysed separately, one could be accused of small numbers problems that might affect the statistical data. But in terms of percentages, (62% of clients, 54% of home helps, 83% of CHNs were interviewed) I think this study is likely to be highly representative of the overall group. Moreover, because the study is concerned more with a qualitative approach, this criticism is unlikely to be upheld. Another criticism that might be levelled from a quantitative viewpoint is that in-depth case studies such as this suffer from the disadvantage of being so context specific, that they are difficult to repeat in other places. Also, they generate a lot of data that rapidly becomes unmanageable, unless only a small number of participants is used. However, I would agree with Bloor and McKeganey (1989: 198) that "...because of the unstandardised nature of most types of service provision...there are no *a priori* grounds for modifying practice in one community in the light of evaluative research conducted in a second community". This study was neither designed to be, nor intended to be replicated. I believe that given the context within which I was working, the case-study approach taken in this project therefore remains the most appropriate way to get at the questions and issues I was trying to ask and understand.

Good evaluation must give you solid information on which to act safely. It should be borne in mind, however, that this evaluation is only one piece of

information that feeds into the whole picture of Home Support Services. The current findings might clarify and provide direction, but they constitute only part of the wider programme. Moreover, rapid changes within the system from both above (Regional Health Authority directives), and below (clients' needs and care givers change), means that evaluation should be seen as an on-going process. Rather than stop with a one-off evaluation at a single point in time, it should be continuously monitored. This doesn't mean having to do formal evaluations on a regular basis, but by continuing to do what the staff of Hauora Hokianga have always done - listening to clients and endeavouring to provide the best services they can under sometimes difficult circumstances.

Research ethics and procedures.

There are a number of potential ethical dilemmas inherent in any research project, and these should be addressed. The main ethical issues to consider are: research sponsorship, research relations, informed consent, the anonymity of participants, data analysis, and data dissemination (Burgess 1984: 185-208). Research sponsorship can profoundly influence the outcomes of a study. Burgess (1984: 195) shows how Research Councils, for example, act as gatekeepers to which studies get funded and therefore what topics are deemed 'suitable' for researching. Commercial sponsorship also affects what gets studied, moreover, the research results may also be modified in both negative and positive ways, particularly if there are various vested interests operating. In the case of this study, I was lucky that my funding came from the University of Bristol and The Leverhulme Trust³. Both sources were neutral in the sense that they had no

³I am grateful to both these bodies for their support.

stakes (financial or otherwise) in the outcomes of this project. Thus I was relatively free to 'get on' with the research without having to worry too much about the end results of the project. However, I was aware that the results I produced could have both positive and negative consequences for the people I was working with, and for Hokianga Health Enterprise Trust. Because of this, I had to be quite careful when writing up the report for HHET, and be sure to back-up my arguments with evidence, as well as preserve everybody's anonymity. This last point also links to two other ethical issues : the anonymity of participants and research relationships (ibid.).

As I have mentioned, I was obliged by the University Ethics Committee to guarantee the privacy of all participants. I didn't think this would be a problem until the research got under way - then I realised that it was extremely difficult to maintain. With only five Community Health Nurses, each with their own 'patch' that was quite geographically and socially different from the others, and with clients and caregivers that highlighted very specific problems, I was worried that participants would be readily identified. In some cases it was quite a challenge and necessitated heavy editing of the interviews before they could be included in the research report for HHET. I found this quite frustrating because much of what I considered to be important had to be omitted. From the participants perspective, many told me that they thought they would be easily identified also. For some this was a problem, whilst others were positively keen to be recognised. However, because I didn't want to run into problems with the Ethics Committee, and because of those who were worried about being spotted, I did my utmost to maintain participant anonymity.

Before starting the study, ethical approval had to be gained from North Health Regional Health Authority. This involved the research project being screened by their Ethics Committee to make sure that the proposed standards of conduct throughout the study were satisfactory. The Committee carefully screened the written information I was hoping to send out to potential participants, and insisted on there being consent forms that allowed for interpreters in 6 different languages, and that required two separate signatures from the participant - one agreeing to take part in the project and one agreeing to be taped. The consent forms also included guarantees of participants' privacy and confidentiality, assuring them that their legal rights or medical care would not be affected in any way, etc. (See Appendix 1). Once the application had been passed by the Committee, the investigation could get under way.

5.8. INTERVIEWING AND THE INTERVIEWING PROCESS.

Mishler (1986: vii) suggests that "An interview is a joint product of what interviewees and interviewers talk about together and how they talk with each other. The record of an interview that we researchers make and then use in our work of analysis and interpretation is a representation of that talk. How we make that representation and the analytic procedures we apply to it reveal our theoretical assumptions and presuppositions about relations between discourse and meaning". Moreover, assessing meaning requires analysing the interview process in order to clarify how that meaning is grounded in and constructed through the discourse of the interview. Yet Oakley notes that although a lot of modern sociology relies on data collected through interviewing, "very few sociologists who employ interview data actually bother to describe in detail the

process of interviewing itself” (1981: 31). I think reflecting on the interview situations is valuable, not only because of Mishler’s comments above, but also because it helps contextualise the study further. It does this by describing the sorts of conditions under which conversations and interviews were held, and how these might have affected the research process, analysis and outcomes. Reflecting on the process of interviewing and its inter-textualities reminds both the writer and the reader of the politics of, and the discursive nature of this type of research, which I have already discussed at length in Chapter 4.

Nearly all the interviews for this study were done in the person’s home. The only exceptions were when a client and a care giver were interviewed together, at the client’s home (on 5 occasions) or when it was more convenient for the participant to meet elsewhere, for example, one of the interviews was carried out in the Rawene Pub (at 9.30 in the morning with coffee only!). These meetings lasted from half an hour to an hour in most cases, although some lasted for much longer. It was found that once the interviews got under way, people would usually answer the questions in the topic guideline before they were asked. For example, as they were recounting the story of how they came to have home help, they would also include details of how long they had the service, how they came to have their care giver and what sorts of jobs their care giver did for them. This meant that the interviews were more fluid and conversational in their nature than if a questionnaire had been administered. This is an important point, because people were more relaxed (and therefore able to speak more comfortably) than if the research had been based on a questionnaire format. I didn’t have to rely too much on the topic guidelines, which could have produced a stiling effect on the fluidity of conversations. Taking this approach also meant

that participants had more control over what they chose to tell or not tell me, although I did ask further questions where it seemed safe to do so.

Mishler argues that “the essential nature of interviewing as a form of discourse has been excluded from the dominant tradition of interview research” (1986: 136). Drawing on Mishler, I see interviews as speech events, - as certain types of discourse that are regulated and guided by norms of appropriateness and relevance. Because the interviews were so open-ended and flexible, I see them almost as ‘story telling episodes’. This story telling, or narrative, is one of the significant ways individuals construct and express meaning. The narratives of the interviews were an opportunity for individuals to express their understanding of events and experiences and what that meant to them. Analysis and interpretation was therefore based on a theory of discourse and meaning, where the meanings of questions and answers were negotiated during the interviews. In addition, I hope that the analysis is also adequately grounded in everyday life in the Hokianga.

Like Mishler, I see interviews as a discourse that is jointly produced by interviewee and interviewer. My role in initiating and following up certain topics and questions implicates me in the construction of the phenomena analysed through my approach to interviewing, my relationships with respondents, the methods I have used to transcribe the interviews and my analysis and interpretation of those transcripts. The dialogue has been mutually articulated and shaped by myself and those present at the interview. I am using the term discourse here to describe the interviews as a sub-set of the broader and more

diffuse social discourses in circulation. I have already examined some of these in previous chapters, for example discourses of health, ethnicity and rurality.

Taping and Transcribing.

With the participants' written permission, I audio-taped the interviews. The main reason for this was so that the conversations could continue unimpeded, without me having to stop and take notes. Another reason for recording the interviews was that it would enable me to keep returning to them to assess the adequacy of my interpretations, even many months on from when they were made. As I was to be writing up 12,000 miles away from the field site, this was especially important. Although I was worried about people's reactions to the idea of being taped, I couldn't think of a more convenient way of storing the interviews for later analysis, or for transporting them back to England. In the event, with the participant's written permission, the interviews were audio-taped. To my surprise, only one person out of 70 declined to be recorded. Extensive notes were made during that interview.

Evans (1988: 210) highlights two considerations when recording data. Firstly, the researcher must detail any background information about the participants, the place where the interview occurred, others present, what people were doing, and anything else which may be relevant, as this may not be apparent when listening to speech or reading the transcribed version. These seemingly incidental factors are important in defining the situations which people are in, and they will have a bearing on the meanings and attitudes offered. This point emphasises the importance of keeping accurate and detailed fieldnotes. Secondly,

the storage of data should be given some prior thought. Where the data is going to be kept has important ethical implications: participants should (in my opinion) have the right to know who has access to their interviews, where to turn should they wish to retrieve their tapes; and under what conditions the tapes will be stored and used. This project was subject to the stringent controls laid down by North Health Ethics Committee. Their requirements are that the tapes are to be stored in a locked cabinet on University premises for at least seven years, after which time they will be shredded by the researcher. In my own case, my university contact, Dr. Robin Kearns at the University of Auckland agreed to store the tapes from this project and will see to their destruction at the appropriate time. I also have copies, which are stored under similar conditions in Britain. They will also be destroyed at the appropriate time. Participants were informed who has the tapes and how to get hold of them at the feedback session in August 1996. It was also advertised in the local community newsletter published by Hauora Hokianga. People know they can phone up the organisation and talk to the CEO or a senior nurse, who will be able to inform them of the tapes whereabouts and how to get hold of them.

A third point, neglected by Evans but that I consider vital, is that what goes unrecorded may be as or more important than what is recorded. It is likely that some topics were excluded simply by the presence of my tape recorder, - my 'Pakeha piece of plastic' as it came to be known. People are often uncomfortable at the idea of being taped - worried about what purpose the tapes might be used for and whether they will in some way be recriminated for their opinions. This might lead them to produce 'public' rather than 'private' accounts (Cornwell 1984, 1988). In this study, for instance, people were worried that senior

management of Hokianga Health Enterprise Trust would have access to the tapes. However many times participants were assured that I did not work for the Trust, and that *no one else* but me would hear the tapes, my gut feeling was that most of them (understandably) didn't believe me. They sometimes expressed worry at the thought of 'getting into trouble' or saying the wrong thing and having their home help services cut as a result. Except for abundant reassurance, there was little I could do about this situation. It was a constant reminder for the crucial necessity of rapidly building a safe environment for participants to speak in, for trust to develop and for keeping the interviews as informal and relaxed as possible. Having with me a highly respected member of the local Maori community (Sara Leef) was a major advantage - participants knew and trusted her, and even though she was an employee of the Trust, people looked to her for guidance in the interviews. Her gentle encouragement and support of participants during the process was something that I would never have been able to give as an outsider.

Having acknowledged that things may have been left unsaid during these interviews, Sarah's guidance undoubtedly drew out themes I would have been unaware of, uncomfortable of, or in some cases, unable to approach myself. For example, some of the discussions about laundry (see Chapter 6), were conducted in Maori, which was far more culturally appropriate than I realised initially. As the research progressed, it became clear that in Maori, certain personal topics (such as laundry) could be discussed without shame or embarrassment, whereas had they been conducted in English, this would have undoubtedly been the case. There are two main reasons for this. Firstly, it was safe for those Maori women who spoke about laundry to talk to Sarah, herself a woman of a similar age and

cultural identity, rather than to me, someone half their age of very different cultural heritage, an outsider. Secondly, Maori is a language where words can have many meanings. Individual words may possess both differing and related conceptual connotations. This means that a conversation in Maori is more enigmatic than one in English, evoking concepts and themes, leaning towards abstractions and impressions. English, on the other hand, tends towards words having a more determined meaning. Many Maori people see English as a crude and rather insensitive language, particularly when it comes to delicate issues. Discussing topics in Maori, however, means that subjects and experiences are alluded to, rather than spelled out directly. Thus talking about personal issues in Maori was acceptable; talking about them in English would have been coarse, vulgar, or rude. Clearly, this created some difficulties in that information given in the Maori language then had to be translated into English to be included in the narrative of this thesis. Here Sarah's help was invaluable, as she was able to translate some of the subtleties into the English language for me.

Although many of the interviews were conducted in Maori, with a person the clients knew and trusted, I suspect that some narratives were going unsaid. We believe there are several reasons for this. Firstly, the amount of formalities to be dealt with prior to the conversations starting put people off. The Regional Health Authority Ethics Committee required that formal consent was signed - and participants found the form most off-putting. Secondly it was suggested that because the interviewers and the research participants were from the same cultural backgrounds, certain taken-for-granted cultural differences might not have been adequately followed up. Thirdly, the interviews were audio-taped and this undoubtedly would have affected what information we collected.

Furthermore, although confidentiality was assured, many people simply did not believe us. Ultimately, like other methods of collecting information, tape-recordings are only partial representations of speech. They do not - cannot - register the whole speech event in its entirety, because they can't capture body language for example, or the circumstances under which the interview took place. On the other hand, they do allow certain linguistic practices to be preserved, for instance, pauses between words, laughter or intonation and pitch. In various ways, these practices can all add to the meaning of the speech event.

Similarly, care should be taken not to take transcripts too seriously as *the* reality. Like the original recordings, they are only partial representations of what went on during the interview. There are several points to bear in mind when transcribing conversations: the mode of transcription adopted should be sensitive to the theoretical model of relations between meaning and speech; they should focus on aspects of speech that bear directly to the study; and the researcher must take into consideration the limitations of the basic data and of resources available for analysis (Mishler 1986: 49). The main resource that I was short of was time. Because of this, only four of the interviews were fully transcribed. With the realisation that time constraints would make it impossible to transcribe all 70 participants' comments, each tape was comprehensively indexed. For the purpose of this study, only certain sections were then transcribed. These transcribed sections contained information regarding Home Support Services (for the evaluation), and other items related to my wider interests, turning mainly around theoretical and cultural questions of ethnicity, health, disability, and the body.

5.9. ANALYSIS AND INTERPRETIVE STRATEGIES.

The first step of the analysis was to undertake a description and several careful readings of the data. On a physical level, I hold approximately 250 pages of interview summaries and transcripts, representing 65 separate interview sessions⁴, of half to one hour duration. This corresponds to roughly 70 hours of interviews and conversations that occurred two to four times a day, 5 days a week over a period of approximately 6 weeks. Most of these interviews were conducted in June and July 1996. On a conceptual level, I have data about the specific local context of Home Support Services, and more general information about cultural and health issues in the Hokianga and New Zealand. The initial task in analysing qualitative data is to find some concepts that help to make sense of what is going on in the data. The conceptual description of the data above is an analytical device for initiating the process of identifying explicit categories. The three main categories that emerged from my data are Home Support Services, cultural issues and health issues. Of course, these categories are not mutually exclusive, and there are many sub-categories, but separating them like this allowed me to organise the data so that an attempt at analysis and interpretation was possible. Several close readings of the data enabled me to become very familiar with it. I needed to look for any interesting patterns, surprises and inconsistencies that were contained within. Certainly there were contradictions among the various views of different groups or individuals who

⁴Some of the participants requested that they and their care giver or client be interviewed together. There were five occasions when this happened.

participated in the study, and these patterns and contradictions are illustrated and interpreted in Chapters 6, 7 and 8.

Hammersley and Atkinson (1995: 208-209) suggest that “the process of analysis involves, simultaneously, the development of a set of analytic categories that capture relevant aspects of these data and the assignment of particular items of data to those categories”. Category construction is integral to the analysis process, because it makes the data manageable and enables the researcher to make sense of it. The qualitative data (the stories, conversations and interviews) were then examined for emergent themes and patterns. These were then selectively ‘coded’ under appropriate headings. Once the data were coded, it became possible to organise them and write them up under general headings, which corresponded to the themes and patterns that had emerged. These themes and patterns are examined in detail in Chapter 6, 7 and 8. Even though most of the tapes were only partially transcribed, there is nevertheless a huge amount of information to process and analyse. In this way, patterns and themes became coded. Sub-categories were constantly changing, new ones frequently emerged. This meant that coding was an on-going, recurring process rather than a ‘one-off’ event. Fieldnotes were also used during the course of categorising and coding. They confirmed the importance of some categories and challenged the logic behind others. In short, they were invaluable in organising the data both meaningfully and comprehensively. I did not aim to divide the data up into mutually exclusive categories. If a piece of information could be accommodated in more than one category, then it was (and cross-referenced). Categories therefore gradually became saturated with information that, in poststructuralist terms, was intertextual, that is different categories sometimes contained the same

bits of data, demonstrating the importance of understanding one category within the context of another. Eventually, the close readings and rereadings of data, and the saturation of categories provided a stable set of categories to be worked with, analysed and interpreted.

Validity and reliability.

Questions of validity and reliability are an issue for concern in any research. Validity focuses on the meaning and meaningfulness of data; reliability focuses on the consistency of results (Patton 1986: 228). Because of the flexibility and individual judgement inherent in qualitative methods, reliability is often weaker than in quantitative studies, but validity is stronger. This does not negate the study, rather it alerts the researcher to the importance of reliability and validity issues and to ensure that strategies are employed to ensure that the study is both reliable and valid.

In qualitative research, validity addresses the 'subjective' nature of data collection and analysis. It is a question of the analyser's interpretation and the plausibility and credibility of their claims. There are a number of other strategies for ensuring validity (Hammersley and Atkinson 1995; Eyles and Smith 1988; King et al 1994). All of them have been used in this evaluation. They include: collecting rich data, as detailed and comprehensive data makes it difficult for a researcher to see what only supports her prejudices or expectations; paying attention to puzzles, because discrepant data or negative cases may help make sense of things; triangulation, where employing multiple sources and methods

will increase the robustness of results; and seeking feedback, where the researcher checks that the interpretation makes sense to those who know the setting especially well. Different researchers sometimes interpret data in different ways and this can be a real problem in qualitative research. One way round this is to get different people to interpret the data, to see if they agree with each other. This was tricky in my case as only I had access to the tape-recorded interviews. I therefore attended regular meetings with Sarah, the Chief Executive Officer and the two head nurses. I would briefly describe the type of information I had to date and what I had made of it. Care was taken to retain confidentiality at all times. We then discussed other interpretations of the material. These meetings were useful because they illuminated and sometimes changed my initial ideas. In addition, they helped contextualise the information further. They were also valuable for the CEO and the principal nurses as it kept them in touch with the study's progress. On one occasion, for example, I relayed some criticisms of the service back to them. The main one was that family were not allowed to be caregivers for clients. The CEO and the principal nurses explained the difficulties of their position in providing the service within the Regional Health Authority's remit. Their explanations helped me understand their position, and the environment in which they operated. In turn, this helped me appreciate why family were not employed as caregivers. As well as these meetings, the study's findings were also critically reviewed by the study participants at the feedback sessions (see Chapter 9).

Reliability is also a matter for concern in qualitative studies. In quantitative studies, reliability hinges on standardised interviews and the swift and easy classification of answers. This is not the case in qualitative research,

where open-ended or unstructured interviews frequently result in lack of comparability of one interview with another. Although in this case the interviews were open ended, there was a topic guideline, which meant that at least the same topics were covered, even if they were dealt with in very different ways. The aim was to gather an 'authentic' understanding of people's experiences. One way of addressing this issue is to use standardised methods and linguistic conventions to prepare transcripts, so that there is some degree of internal consistency in their arrangement. This strategy was used in this study. For instance, square brackets indicate where I have added words, and three dots shows that words have been left out, both for easier reading. Double quotation marks (" ") are used for verbatim quotes, single quotes (' ') are used for paraphrases. This helps make the search for consistency within the transcripts more easy.

5.10. CONCLUSIONS.

This chapter has examined some of the methodological issues pertinent to the project. I have proposed that qualitative methods such as ethnography, narrative, participation and fieldnotes are the most appropriate ways of undertaking a study such as this, where the need for flexibility and discretion is paramount. The research methodology was designed for the most immediate issue at hand, which was to evaluate Home Support Services in the Hokianga. It was hoped that material for my other interests could also be gathered along the way - as almost incidental to the main task at hand. This is not to say this information was covertly collected, but that it was of secondary importance to the primary purpose of the evaluation study. Trying to achieve a successful outcome

for both endeavours (the evaluation and my own interests) meant that a wide and disparate set of literatures had to be drawn upon.

In this chapter, I have tried to bring together the many divergent streams of theory and practice that informed this project. This was no easy task, and I think that this is reflected in the disjointed nature of the chapter. Aiming to do different things for different people has further complicated the issue. For example, it has meant trying to design the methodology in such a way that it would be suitable for two different purposes - the formal evaluation as well as my wider interests. It has meant writing about different things for different audiences, as well as trying to connect very dissimilar literatures, in an attempt to carry out both research undertakings successfully. Interpretation and analysis of the data is dealt with more in Chapters 6 and 7, but I have briefly introduced some of the salient ideas guiding me in this chapter. This is because I believe that analysis starts the minute you conduct the interview. It is not a clear-cut and well-defined operation, rather it is a continuous processing and transformation of the data, that carries on throughout the whole duration of the project. Approaching the data this way makes them open for eventual systematic and thorough analysis, so that meaningful and promising findings might be generated. These findings are discussed at length in Chapters 6, 7 and 8.

CHAPTER 6. DISCOURSES OF HOME HELP 1: RURALITY, 'RACE', ILLNESS.

“Tony [Birch, Medical Director of Hokianga Health Enterprise Trust] had an interesting idea on Monday. He mentioned that a lot - in fact most rural health research seems to be coming out of rural South Island - not North Island. Why is this? Tony thinks it is because Northland has mainly Maori and their voice is not so well heard...” (Diary 2, 27.3.96.)

“The strengths are that it is a small community, that people doing the work are people *of* the community *for* the community, and that the community understands you know, the needs that are particularly and really different from an urban situation.” (Elizabeth, Community Health Nurse)

“Home help - how I hate that word! It makes you sound so helpless!” (Ruth)

6.1. INTRODUCTION.

In Chapter 2, I outlined the theoretical concepts informing my analysis. They are concerned with notions of discourse, otherness, and the body. The following three chapters relate these concepts and ideas to the empirical work undertaken for the thesis. In this chapter, I present a broad overview of otherness in terms of rurality, ‘race’ and illness. I also explore some of the links between them, and consider how they impact on each other. In Chapter 7, I focus on specific discourses of home help, and account for their variations between different sections of the Hokianga population. Even more specific, in Chapter 8 I examine discourses of the body. I then situate them within the wider New Zealand context.

Discourses are sets of textual arrangements which organise and co-ordinate the actions, positions and identities of the people who produce it. They are the modes of textuality that allow an institution to operate, locating and orientating talkers with respect to one another. They therefore define protocols (ibid.). Put simply, discourses are made up of mutually reinforcing - and opposing - narratives and practices. Narratives and practices are interlocking components which contribute to the view that home help is but one of many discourses operating in the health and social domain. Examining narratives and practices that are in current circulation within the home help arena can be seen as a very practical application of how discourses can shape the experience of reality, as well as being shaped by that reality. Taking narratives seriously means taking local knowledges seriously (Gourley 1993: 364). This entails a close examination of the politics of health talk nexus, which is intersected by both lay and professional discourses. Moreover, this nexus, and these discourses, are further complicated by other factors, for example geographical particularities, ethnicity and rurality. This chapter, and the two that follow it, consider some of the discourses and practices that contribute towards this politics of health talk nexus, as well as facilitate understandings and meanings of home help for people in the Hokianga.

Like discourses, narratives are temporally and spatially situated; therefore they need to be grounded in the social and political concerns that produced them, that is, the social conditions under which they emerged. I have already done this in Chapters 3 and 4. In those chapters, I discussed how stereotypes of otherness in terms of 'race', illness and rurality have developed. This chapter extends these ideas, by examining home help narratives that focus

on marginalisation and otherness, in terms of: (i) rurality; (ii) 'race'/ethnicity; and (iii) illness and disability. These diverse yet linked aspects of shared, group identities were an important feature of the home help stories, although each topic appeared with varying frequency.

These stories were gathered during my time evaluating the home help service for Hokianga Health Enterprise Trust¹. The narratives are grouped together in a way that show some of the connections - and fractures between facets of rurality, 'race', and illness/disability. They also show the 'betweenness' of people and discourses: that people, and narratives do not necessarily 'fit' easily into any one category, and that they can often fit into more than one category. The stories also show that people and discourses are criss-crossed by infinite numbers of other discourses and other experiences, all of which shape the stories I was told. In order to examine this triangulation of rurality, 'race', and illness, I first separated Maori narratives from Pakeha ones. Within these two categories, I sub-divided the stories into those told by men and women, and then old people (those of pensionable age) and young people. Admittedly, these categories are arbitrary, and analytical constructs only, as is my triangle of rurality, 'race' and illness. However they also serve as a tool that enables me to

¹It should be noted that the interviews were not treated as straightforward reports on reality, but as conversations that were actively structured and restructured by the interactions between interviewer and participant - the interview process. Thus while I might make much of these conversations, I do not necessarily take them as undisputed 'truths'. I acknowledge that they may include contradictions, comments made for political purposes and conflicting representations of the situation. This reflects precisely my description of discourses. They are not naturally occurring, free-standing entities, but shaped and reshaped by preceding discourses and social relations.

make sense of, and comment on the stories I was told. Instead of relegating the biographies of the participants to an appendix, I introduce them as I recount and analyse their stories². I have chosen to do this because I suspect that putting biographies into an appendix would dislocate them from the stories and experiences I was told. In addition, keeping tellers and their stories together serves to further contextualise the project.

6.2. DISCOURSES OF RURALITY.

Traditionally, the rural has been defined in terms functional categories, that is land use and geographic location. Increasingly, however, notions of rurality are recognised as social constructs. The rural can therefore be understood as a domain of social, moral and cultural values in which rural dwellers participate (Cloke 1994: 539; Watkins 1997). At one level, this domain consists of rapidly changing political and economic environments. At another, it comprises more humanistic concerns, such as individual experiences and meanings associated with rurality. According to Cloke the task of rural geographers is to

“investigate the cultural arena so as to understand how different constructs of rurality are linked with power relations, social conflict, economic commodification, residential colonisation, environmental recomposition and the many other key concerns of contemporary rural geographers” (Cloke 1994: 539).

²I have changed the names of the participants, in order to retain anonymity.

I consider discourses of rurality (and home help) here because doing so gives a sense of what living in the Hokianga is like. It also suggests ways in which people are othered and marginalised vis a vis their urban counterparts, and how experiences of home help might differ from an urban area.

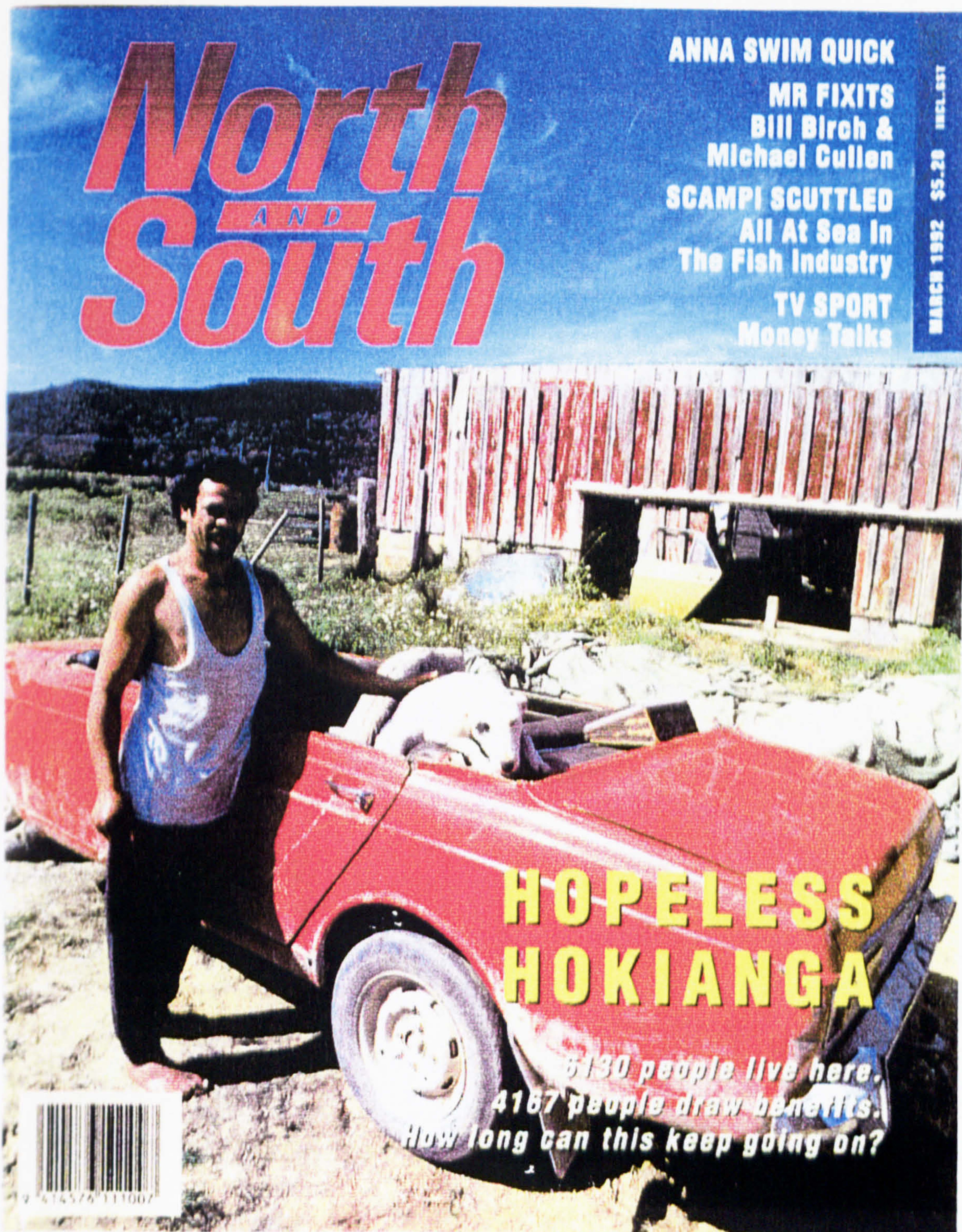
The cultural arena of the Hokianga is situated within the wider New Zealand context of political and economic activities, a complicated, ambivalent mix of Maori and Pakeha traditions and lifestyles as well as global influences such as TV, the Internet and foreign travel. This arena, and its embeddedness, greatly influences discursive formations of rurality in the Hokianga. For example, some of the older Pakeha people I spoke with had retired to the Hokianga because it was such a beautiful place. Drawing on notions of the 'rural idyll', they had settled here only to find that life was not necessarily as idyllic as they had once thought. Over time, these notions had faded and had been replaced with much more pragmatic views on rurality: how to get around in the mud, the isolation, and the experience of getting old away from families and friends. Others had lived in Hokianga all their lives. Talking to these people about rurality and what it meant to them was hard work - they simply did not think of the Hokianga in these terms at all. Yet others, who had also lived all their lives in the Hokianga had quite definite ideas on what rural living meant. The diversity of experiences and opinions was a constant reminder that discourses and narratives rarely dovetail neatly into a story with closure. Instead, there were many contested ideas of what rural living means.

Conceptions of rurality in the Hokianga draw from both functional and socially constructed categories. Functional definitions of the rural in the

Hokianga include land use and geographic location. Social constructions of the rural build on notions of the rural as a 'frame of mind' and include ideas of rural-urban differences, the rural idyll, and physical geographic location. For example, Matiu, an elderly Maori man, who receives home help, told me:

“We live in the last place God made! Although its a beautiful area, its way out in the sticks all right. We're isolated - but what can you do about it? Hokianga has it's own way. Its own style. It's own lifestyle, eh? They don't give a damn in Auckland. Dog eat dog there. No place like home, yeah.”

Social and cultural spaces, including those of the rural are about particular social constructions that people hold - both insiders and outsider. Concepts of rurality can also evoke notions of marginalisation, social isolation and difference. These concerns can be both exacerbated and reinforced by the media, for example, the cover page of *North and South* magazine, overleaf. 'Hopeless Hokianga' has thus had social meanings attached to its rurality both from without and within. To my mind, functional and social definitions of the rural operate along a sort of continuum, and somewhere between these two poles, is a spot where very real conditions in the Hokianga influence (collective) frames of mind and by extension, group and personal identities. These are concerns largely outside the control of Hokianga residents, and consistently serve to reinforce their difference from mainstream New Zealand. They include the vagaries of the weather, particularly the rain; poor roading and public transport problems; and unemployment. Stark in their reality, and harsh in their effects, these tangibles feed into social constructions of rurality in the Hokianga, further compounding ideas of difference and otherness. The cover page of *North and South* overleaf supports this argument.



VISUAL DISCOURSES OF DIFFERENCE: 'HOPELESS HOKIANGA'.

(Source: *North and South*, March 1992)

In the British context, rural social space is increasingly becoming freed from rural material space, as a result of changes in political economy and society. In Hokianga, however, I believe these kinds of changes are of a much lesser magnitude. This is not to say that they are static, but that rural social space in the Hokianga remains intimately tied up with rural material space. As a result, most of the constructions of rurality by Hokianga residents that I heard were thoroughly pragmatic. In addition, some research in Britain highlights the problems of rural deprivation and the experience of marginalisation, where people are made to feel not part of a community. Some authors have pointed out that often, rural lifestyles not conforming to the rural idyll are being neglected (Cloke 1994; Philo 1992; Sibley 1995). However, in the Hokianga, where rural deprivation is common, this occurs to a much less extent. In terms of socio-economic deprivation, most Hokianga residents are poor, most are on benefits and a significant percentage of housing is inadequate (Kearns 1998). This means that otherness, in the form of a socio-economically marginalised identity, occurs at a group level, not at an individual one. And in contrast to other areas, 'alternative lifestylers' for example, new agers, hippies, and tramps, what Philo (1997), following Doel (1994) has referred to as 'the Other of the Other', - usually all forgotten from view - are very much a part of the Hokianga scene. The stories that follow are interesting because they suggest that at a local level, 'the Other(s) of the Other(s)' are not necessarily viewed as Others at all in Hokianga, but are visible as merely part of everyday life.

For example, Pippa is Pakeha. She is 53 and originally from Christchurch. She has been in the area for quite some time now, and has been a

home helper for about a year. She described to me her ideas of what living in the Hokianga was like:

“We travel on unsealed roads - that’s another thing about the Hokianga - they call it Hokianga time - you know like for instance when they call a meeting - “What time’s this meeting starting? “Oh, when there’s enough kids here!” so there’s a situation where things don’t happen very fast. A lot of people live in caravans. A lot of people live in - I assume they would have been old railway huts or old workers huts that they might get two and put them together. They don’t always have electricity, they don’t have power - we don’t have things like a rubbish collection, a lot of these homes don’t have water, but um, they don’t really have adequate housing. It’s very basic. A seat would be a plank of wood with a couple of beer crates hammered on it...there are places where getting onto property - there are places you have to drive along the beach to get to [so the home help has to coincide her visits with low tide times] or you actually drive through paddocks you’d never get out of there if it was raining! You don’t get out around here in dainty or feminine clothes - high heels and that! In the summer we have jandals [flip flops] and in the winter we have gumboots. And if they leak you just put bread bags on before you go out. They’re Hokianga socks. And water - we rely on the rain - we watch our tanks right up until about April...you don’t pull a bath - September you start taking it easy because you really want to top up for the summer because if you haven’t got that six thousand gallons - well - you’re done. All your vegetables and everything. A lot of people don’t have electricity and this was the beauty of me coming into the area. You see I had been living like that anyway...this area is *so* isolated...”

Pippa pointed out to me that many people did not live in conventional housing, and that the furniture inside could be home-made from all manner of materials. Likewise, Janine, one of the Community Health Nurses agreed. Janine is Pakeha, I would guess in her early forties. She has lived in the Hokianga for many years, and has spent a large part of her time farming. When her oldest child was five, one of the other community health nurses went on holiday, and Janine filled in for her. The following year, she took up a full-time post.

“I fell into public health by accident. When I started in public health fifteen - twelve years ago, I used to go into homes where there were new children, new babies - the odd dirt floors, no power - I hardly see that anymore. The housing problems I see are overcrowding. Where people have been black listed by the Housing Corp and are not in charge of their lives at all. I have a few families with chronic ongoing impetigo, and that's to do with living in cowsheds, or garages and not having water. Not having water to wash. And washing kids clothes and washing kids bodies...There's one European guy, I want him to have home help. He's lived under hedges most of his life but he refuses flatly because he doesn't want - if anyone comes to help him he wants them in because they want to be there, he doesn't want them paid to be there...he's in a house at the moment and its filthy, just absolutely the pits. And its disgusting. But he's happy”.

These kinds of living conditions are not uncommon features of Hokianga life. And because the climate of Hokianga is so mild, heating a home is not as important as it might be further south in Aotearoa/New Zealand. When I asked Ruth (introduced previously in Chapter 4), about living in a place with no power, she retorted:

“Pah! Who needs power?! Who wants power? My kids want to put power in and I say yeah, they can put it in as long as they can pay the bills! I used to have a generator. I have gas [cylinder] now.”

Although most people I spoke with did live in traditional style houses, there were some that did not. As I outlined in Chapter 4, Ruth for example, lives in a metal garage. And Evelyn's place, also mentioned in Chapter 4, is a lean-to built onto the side of a caravan. But both were habitable (although I admit, I would find them difficult to live in because of my privileged upbringing and lifestyle), both were well looked after, both were somebody's home.

The geographic area that Community Health Nurse Elizabeth covers is directly adjacent to Janine's, but it could not be more different. Whereas Janine's patch is mostly Maori, and sparsely settled, Elizabeth's patch is mostly Pakeha in a village, with Maori people tending to live in much more isolated areas. Although like Janine, Elizabeth is a Community Health Nurse, Pakeha, and roughly the same age (perhaps a few years younger), her background and experiences are quite different from Janine's. This is reflected in the ways she sees the Hokianga.

“[Poverty] is relative, and it's something that I have difficulty with - because I come from Africa and see er, what may be *true* poverty. But relative to New Zealand, - educational poverty...the disempowerment of Maori people over a period of years has resulted in a combination of dependence on the system - benefits and so on...[T]he area that I work in is very unusual in Hokianga because the village of Kohukohu is by and large inhabited by people who are very well educated and have made an active choice to be here and change their lifestyle. So there is a conflict. So I think although they may be on a benefit, because of the education and life background, they come to the area and live a very rich life. because they know how to *access*, they have the information, they know how to do things, they know how to work the system...So on paper it would look like people are very disadvantaged but a lot of them have university degrees or the ability to get them,...therefore, I feel that people here - and mainly of course I'm talking of the Pakeha community live very wealthy lives...By contrast the Maori community don't have that background of education. I think that in the past Maori people have either in this area gone off to school and have then gone on to further education which takes them out of the area. There are not that many Maori people in my area who have come back educated and therefore educating their communities.”

“In terms of the poverty, its the poverty of life experience that I find the most distressing. [Its hard to describe the worst kinds of poverty] because of my background. I see it not so much as bad conditions, as ugliness. Ugliness when people have got a place - I - I - have seen people - I've got somebody in my area who built their house entirely from recycled material. They recently got electricity which is great. They've got running water now, and they didn't before. This

woman used to wash the nappies in the machine - she used to bicycle as a motor but their house is really beautiful. Its all painted, they've got calf skins on the floor, there might be flowers, and so to me, although to a city person it might be a very poor sort of shack, to me, if its got the basics, um, they don't have a flush toilet, but its very beautiful. On the other hand I might go to a place where its very ugly. Pigs and dogs and everything right up to the front door. Lots of rubbish around ...the streams that people get their water from is quite questionable...yet there's a house that's got running water and what have you that I've been into and they're cooking possum and its - the *whole* house! I have to gasp when I go in."

For Elizabeth, the poverty she might see is not as bad as what she saw whilst growing up in Africa, and might not be as pressing as Janine might see in her area. 'Alternative' Pakeha lifestyles are common in Kohukohu, and, according to Elizabeth, they live very rich lives. But Elizabeth's comments are telling because they suggest that whilst many Pakeha have chosen to live in a certain way, many Maori people have not had any options as to the ways in which they live. Elizabeth blames this on poor educational opportunities for Maori. Moreover, from her comments, it seems that those Maori who have managed to break into the educational system, chose not to return to the Hokianga. And because it is part of the Hokianga, Elizabeth's area is still as seen as poor and rural by other New Zealanders. Here I am reminded both of the previously mentioned article in North and South, ('Hopeless Hokianga') and of the couple who took me on the vintage car rally:

"They've got rules of their own up here...what would you want to build a house up here for...you would think arriving here that you'd come to the end of the world!" (Diary 1, 30.4.96)

Not everybody in the Hokianga is the same, or in the same position as these examples, but neither are these just isolated cases. They are just everyday

people and everyday stories in the life of the Hokianga. Yet these examples serve to emphasise the differences between and within rural areas, as well as rural areas compared to urban ones. The stories suggest to me that collectively, the Hokianga is perceived as doubly jeopardised by outsiders - a rural other, 'the Other's Other', if you like, as well as a rural area with others in it. Indeed, within the Hokianga, I found the issue of otherness is very murky. What do Hokianga residents consider to be other? There was little evidence contained within the stories I collected. As evidenced in the stories that follow, much more prominent was the idea that it was Hokianga *collectively* that was different from other rural areas, and different from the rest of New Zealand.

These discursive formations of rurality eventually sweep into health issues, and when discussing home help, certain 'rural' themes came up frequently. From a pragmatic viewpoint, there were many comments on the difficulties in getting around the Hokianga in the winter, because of the poor roads and the mud. There were also stories of what it was like to be a home help in a house without power or running water. And in contrast to Spooner's (1997) findings in the Waikato, judging by the frequency it was talked about, isolation was perceived as a big problem. But there were also stories of how both the community and the home help service fostered social relations of a special kind, simply because they *were* a rural community. The following tales promote a positive view of the Hokianga as an area united by circumstances rather than divided by difference. Hine, an elderly Maori woman receiving home help told me that

"We're not in the rat race like in town. Things are more slower. Just take it in your stride. And things are much more different

than in the city. *Much*. And things are more safer...You got a neighbour that you know, that you can go across and well, pick her up on the street and have a talk with her, you know? [With a stranger] you feel iffy! You don't know the person - well, I've never lived in town...lived in this area all my life."

Winnie agreed that rural living, and Hokianga living made a difference to the experiences of home help. She and her elderly mother are Maori. Her mother is senile, and needs help with all activities of daily living. Nancy, the home helper for Winnie's mum, is Pakeha. Here, although Winnie acknowledges that things might be different if her mother had a Maori caregiver, Nancy is just like *whanau* (family) anyway. And that's because, according to Winnie, in the Hokianga, Pakeha people fit into a Maori way of life:

"I think home help could be different in the Hokianga than in the town.. Because a lot of home helps here - they're more like family, aren't they? Or should I say they're Maori - like ourselves and family - and I'm sure that if I had a Maori person come in here and look after mum - you know - things would be different. Whereas in Auckland - their lives are so fast and everybody's just there to do their jobs...the dollar...even the European ones in the Hokianga - they're more like *whanau* aren't they? They get to understand our way of life...She's Pakeha, but she's got Maori *aroha*³. That's how she is in her own life...I wouldn't change her for anybody. I wouldn't take her out for *whanau* either..."

³*Aroha* is defined as affection, compassion, pity, sympathy and love (Biggs 1990). In a more sophisticated discussion, Barlow (1991) describes *aroha* as a concept, rather than a word, because it encompasses so many different, but related concepts. According to him, *aroha* is a sacred power that emanates from the gods. In a person, it is 'an all-encompassing quality of goodness, expressed by love for people, land, birds, animals, fish, and all living things. A person who has *aroha* for another expresses genuine concern towards them and acts with their welfare in mind, no matter what their state of health or wealth. It is the act of love that adds quality and meaning to life.' (1991: 8).

Hilary had many interesting things to say about rurality and health. She is Pakeha, in her mid-late thirties, and has lived in the Hokianga for sixteen years. Her son was born in 1991. He has a high level of special needs, and is also severely epileptic.

“I live in the Hokianga basically because I think its a really good community. I’ve got a lot of friends here who are really special. Who are really important. When my son was born with special needs I was asked by all the medical teams in Whangarei if I wanted to move down there because all the services are better - theoretically. And I said no because I wanted to live up here in my community and where I knew people and who could support me here...And yeah - it’s my home...Basically I’ve lived in the community for sixteen years and so I’m quite well known by a lot of local people...And in times of stress and everything they know that - you know I’m not going neurotic - they know me so well! You build up a level of trust and understanding which I feel is really important. It’s almost like a family kind of situation. And when (my baby) was born I had come to terms with not only the fact that he had a disability, but the fact that I’m a solo mother and his father doesn’t have anything to do with us. So I’m basically on my own. And I came to the conclusion that I could cope with all this because I saw (my baby) as a child of the community. And at times, I’ve had to ask - you know - people for help. And people are always really happy. Our isolated rural community - that’s sort of in terms of how the rest of the world look at us. That’s sort of like a term that they see that stays with you and its isolated in terms of distance to city services, I guess I’m trying to say...It’s becoming less and less isolated. But - and also, in terms of roading because the roads didn’t use to be sealed into the Hokianga - but that’s changed now. But that’s sort of isolated in that it’s so far. And also isolated in the sense of poverty. People are really poor. Like I would maybe go to Whangarei once a year because like - you know, that’s sort of like what I can afford to do. I maybe go into Kaikohe once every two to three months - coz I can’t really afford the petrol. So *geographically*, there’s isolation...”

From these comments it is clear that there is no one single rural space, be it social, material or whatever. Instead, there are a multiplicity of ideas superimposed on each other. Groups and individuals trace out their own

complicated geographies in the same places, with different aims and results. These multiplicities provide the grounding for different stories of the same, or similar reality. Sometimes these traces coincide and collide, sometimes, they do not. Similarly discourses of 'race'/ethnicity intertwine with issues of rurality and illness, and it is these coincidences and collisions to which I now turn.

6.3. DISCOURSES OF 'RACE'/ETHNICITY.

In Chapters 3 and 4, I have already suggested that cultural identity makes a difference to health; that the two are inextricably linked. Access to knowledge, language, land, cultural institutions and society all play an integral part in a person's well being, be they Maori or Pakeha. Yet historically, Pakeha have enjoyed these things at the expense of Maori. In Hokianga, however, things are slightly different. Maori cultural institutions (for example, *marae*, *whanau*, *hapu* and *iwi*) are as much a part of daily life as Pakeha ones (for example the church, schooling). This has not been the case elsewhere in New Zealand (Orange 1987). Kearns (1998: 493) has argued that because there has been less land alienation in the Hokianga than elsewhere in New Zealand, local people claim "...there is spirit of one *iwi* in Maori and Pakeha relationships" (HHET 1994; 1995). I am left slightly unsettled by this assertion. At a general level this might be true, and Hokianga residents really do pull together in a crisis, but at a mundane, everyday, individual level, when there is nothing in particular around which to mobilise, I heard stories that hinted otherwise. Thus although the previous stories suggest the Hokianga is a cohesive unit, on closer inspection, there are definitely tensions within.

For example, the apparent spirit of one *iwi* and cultural tolerance does not necessarily mean close mixing. The monthly Men's Day meeting in Rawene is a popular venue for gossip and exchanging views. I was told that:

“...especially the retired chaps go. The Maori men stand in one corner, talking about fishing, eeling, and the old days, the Pakeha stand in another corner, talking about finance. It's two different worlds and the Maori guys certainly aren't interested in money!” (Diary 2, 30.5.96)

Some stories I heard did rather more than hint. Mary is Pakeha and nearly ninety. She has lived in the same tiny settlement all her life. She told me:

“The Maoris are good people. I don't have any trouble with them. Even all these ones up here - they live in funny houses but they never bother us.”

But it was Josie's comments that intrigued me most. She is a Pakeha woman, a retired teacher, in her late eighties. She moved up to the Hokianga from Christchurch over fifty years ago, to teach. She married a local Maori man. They have four grown-up children, some of whom live in the area, and some of whom do not. In the first part of our meeting, she described the special collective nature of the Hokianga, and the impact this has on home help in the area, as a function of the closeness and togetherness of Hokianga people:

“I think in a city - it would be more - without the feeling. I think there'd be more feeling here than in a city. I think there it would be more matter of fact, come and do it and go sort of thing. Where as up here, there is a peculiar kind of feeling. I can't call it - kind of like a relationship or something is perhaps the best way I can describe it. There is something together about the Hokianga people. The fact that you come from the Hokianga - is a big thing. It is a good thing...”

But as our conversation evolved, Josie said some things that surprised me, particularly as she was married to a Maori man (who, incidentally, was not present during our conversation).

“I didn’t want a Maori girl [as a home helper]. Because they pinch things. And I knew [my Pakeha home help] was perfectly reliable and honest. And a Maori girl can be so charming, but they don’t *know* how to do things. Like with [the Pakeha home help] I can say, ‘Will you vacuum, will you do this, will you do that, and she’ll *know* how to do it. But a Maori girl, I would have to show them and at that time I really wasn’t well enough to - to go over and over and over it again. I’ve had Maori girls in the house before and *every single one* has pinched stuff. Even my brassieres. They’ve pinched bracelets, they’ve pinched scarves, they’ve pinched everything. You know - little things- they just hide them under their clothes and take them. Well, I don’t want anything touched in my house...”

These comments took me by surprise and I really didn’t know how to respond to them. I had imagined that a highly educated Pakeha woman, who had been married to a Maori man for almost fifty years would be more ‘pro-Maori’. This to me was a blatant case of constructing racist discourse through creating stereotypes. And as I talked to more people, different stories of stereotyping became more apparent. For example, Theresa is Josie’s home helper. She has been in the area for 16 years. She and her husband have a farm, on which they are struggling to survive. She told me:

“We lose about 30 sheep a year. And we know it’s the blacks. We just can’t prove it.”

Gertrude, an elderly Pakeha recipient of home help, suggested that Maori were similar in lots of ways. She has had home help since she had a below knee

amputation two years ago. Her home helper, is Maori. When she was talking about her home help, she told me that:

“...her only problem - or the only problem actually is as with a lot of Maori people, they've got very large families and always somebody on call you know - that needs her for something or she's got to go down and somebody's ill you know...she's not a good time keeper. But a Maori person will always get a job over a Pakeha...”

When I looked more closely at these instances, I began to realise there was a pattern to them. The Pakeha commentators were all women, *none* of whom had been born and raised in the Hokianga, even though some of them had been in the area for fifty years and more. They had all come from bigger places in New Zealand, for example, Christchurch, and Auckland. The Pakeha men in the study did not mention anything along these lines; nor did the younger people in the study who received home help. This might just all be coincidence, that these comments were made by one subset of the home help population. But considering approximately 70% of the participants were Maori, it seemed interesting that this Pakeha group of participants had such definite and stereotypical ideas.

I began to look for cases where Maori participants stereotyped others. Interestingly, I found that this was happening, but in a different way to Pakeha stereotyping. The stories recounted by Pakeha had concentrated on Maori. The Maori stories of stereotyping that I collected also concentrated on Maori people, not as I had imagined, Pakeha. For example, like many others in the project, Moana, the middle-aged daughter of a Maori lady receiving home help, told me that:

“Maori people on the whole tend to be more accepting of what’s going down - they don’t question it and so maybe they are getting less of a service than what they might get elsewhere? It takes a while to break through the Maori reserve...Maoris are like that eh? They don’t...complain...”

And Janine the Community Health Nurse Commented:

“There was a woman who was quite sick after she had broken her leg. And very strong on the marae. And very strong. And she insisted that she did not want a Maori home help. She wanted a Pakeha. She herself was Maori! She was quite hot on that. She wanted everything done. She didn’t want anyone ringing and saying ‘I can’t make it today’, or ‘The car’s broken down’. She wanted someone there *bang on* the time she wanted things done in the morning and she wanted them out of there at a certain time. Her idea of having someone reliable was someone who had a car that went.”

What do these comments tell us about Maori people? Apparently, that they live in funny houses, they steal, they are invariably late, they do not have reliable transport, they do not complain, and yet for all these characteristics, they will “still get a job over a Pakeha”. When it came to Maori representations of Maori, clearly, they saw themselves as different to Pakeha, although this was not articulated as such. Maori perceptions of Maori are that Maori are humble but proud folk who feel unable to complain, for whatever reason. Maori perceptions of self are therefore very different to Pakeha perceptions of Maori, although there are instances where the stereotypes are the same (as in the stories above). Moreover, the fact that Pakeha did not stereotype themselves suggests to me that they were operating within a taken for granted framework where Pakeha weren’t spoken about simply because there was no need - they were, indeed, the norm.

Although New Zealand is widely perceived as an egalitarian society, and although 'race relations' in the Hokianga have traditionally been better than elsewhere in the country, stereotyping is clearly apparent here. Of course, racial assumptions vary widely from person to person, but I found it interesting that such stereotyping and perceptions of Maori were so distinct during these interviews. And it was definitely one-sided. Pakeha (who were mostly elderly women) offered their versions of what Maori people were like frequently. Was this because I too was Pakeha? Did the older Pakeha hold different views from the younger participants? Rarely did I hear Maori grumble about Pakeha in the way I heard Pakeha grumble about Maori. Why was this? I'm sure they must have had things to grumble about! My assumption is that Maori tended not to talk about Pakeha in such a derogatory way for fear of offending me. Also, I was dealing predominantly with an older generation of people (Pakeha and Maori) and my understanding is that older Maori are less verbally forthcoming on these sorts of matters than their younger counterparts. Even so, I was surprised at the forthrightness of some comments, especially in an area renowned for its harmonious bicultural way of life.

Stereotyping is a representational practice that is always in some way connected with exclusionary discourses. Hall (1997) argues that stereotyping essentializes, reduces, naturalizes and fixes difference. It reduces people to a few simple, essential characteristics, as the above narratives suggest. Stereotyping also employs a system of splitting where normal and acceptable are separated from abnormal and unacceptable. Everything which does not fit into the acceptable category is then excluded. "Stereotyping...practice[s] closure and exclusion...[it] symbolically fixes boundaries, and excludes everything that does

not belong” (Hall 1997: 260). Stereotyping is therefore part of maintaining social and symbolic order. It sets up a symbolic frontier and forms imagined communities of Us and Them, Insiders and Outsiders, Self and Other.

Stereotyping occurs where there are power differentials between groups. Power is usually directed against the excluded group, so that ethnocentrism becomes a feature of this process and the world view of the powerful group becomes seen as common-sensical, natural and inevitable. In this way, stereotyping is directly affected by spatiality - the human and social implications of space, the formative constitution of society (Giddens 1984; Soja 1985), and “the ways in which power-knowledge are inscribed in space and through which particular subject positions are constituted” (Gregory 1993; 1994: 584). In many ways, I think Maori have long been aware of this spatiality, although not necessarily in such academic terms. One way they have resisted Eurocentric power and domination is to protect their cultural heritage and knowledge. This brings to mind the earlier story about the men’s day at Rawene Town Hall, where the retired Maori men talk about fishing and eeling and the Pakeha men seem more interested in money (Diary 2, 30.5.96, see page 191, this Chapter). There has been much debate on who ‘owns’ Maori knowledge, that there is *mana* in some kinds of knowledge and that care must be taken as to how and with whom it is shared. Maori are often faced with apathy even hostility from dominant group interests when attempting to promote cultural value systems that are important to them. Race relations of the past and in some ways today ignore their indigenous position and have been aimed at assimilating Maori into the (Pakeha defined) mainstream.

Up until recently this has been the case in health matters. However, certain key publications have become widely available, that whilst not necessarily giving away 'medical secrets', do help others from a different cultural background begin to understand Maori concepts of health. This in turn has produced an affirmation of Maori difference. The process of cultural distinctiveness is viewed by an increasing number of Maori as an essential element in the process of building self-esteem (Rolleston 1989: 31). And this resistance and self-esteem contribute to people's health status (Durie 1994; Murchie 1985; Rolleston 1989). In the next section I turn to issues of illness and disability, and begin to investigate whether Pakeha discourses and narratives are different from Maori ones. In doing this, I am aware that once again I might be accused of essentialising the categories Maori and Pakeha, old and young, male and female, but I also acknowledge the many crossovers, fuzzy borders and differences, both within and between individuals, regardless of their 'race', age or gender.

6.4. DISCOURSES OF ILLNESS AND DISABILITY.

Illness reminds us that the 'normal' functioning of our minds and bodies is central to social action and interaction (Nettleton 1995: 69). From this viewpoint, illness sheds light on the nature of the interaction between the individual, the body and society. If you cannot rely on your body to function 'normally', then relations with the social world are affected, for example, through an increased dependency on others, or a challenged sense of self. For example, the inability to determine precisely one's body movements means others have to do things for you, and in a culture that emphasises self-help and

independence, this threatens a person's self-esteem and identity. Social interactions which are based on reciprocity can be precarious precisely because an ill person might not be able to respond in what is deemed the appropriate way. Therefore the nature and experience of chronic illness has sharp repercussions on everyday life. Social relationships, identity and a sense of self can be profoundly affected. Responses to illness are thus not mediated entirely by biological and physical symptoms, or individual causes, but shaped by, and shot through, with the social, cultural and ideological context of a person's life. Illness is therefore both a private and a public affair.

In western culture, chronically ill people live in a world where independence is valued and making too many demands alienates you from others. So how do people cope with, and make sense of their illness? And how do these interpretations impact upon action? How people interpret and make sense of their illness experience, and what it means to them is of paramount importance, because the relationship between the body and the self is disrupted. (I examine ideas of the body further in Chapter 8.) Illness is constructed through meanings and interpretations, which structure how people behave in the presence of certain symptoms. Illness can therefore become part of a person's identity. People who suffer with chronic conditions face a world full of uncertainty. Through various coping strategies, they manage an altered experience of self and identity, as well as signs and symptoms, in order to keep up the appearance of 'normality'. Keeping up the appearance of normality brings me back to both the aims of home help and notions of dirt as matter out of place (Douglas 1966) that I introduced in Chapters 2 and 4. Home help aids people in maintaining a sense of 'normality' about their everyday life. Dirt offends against

order, and efforts to remove it are attempts to organise and purify the environment which has become disorganised, and abnormal, through illness. The house is kept clean, so that standards are maintained and social conventions are followed.

As part of the home help evaluation, I asked people to describe their difficulties. Most of the answers I got were connected with health problems associated with old age, for example strokes and arthritis. But the attempts to maintain a facade of 'normal' everyday life has had great implications for the study. I found that people tended to understate their chronic health problems and related difficulties. Although some admitted they could not manage very well without their home help, a significant number said they could, and comments such as those that follow were plentiful. For example, Bobby is Grace's husband. They are both Maori, and in their mid-fifties. They returned to the Hokianga about six months ago, following Grace's stroke. Bobby told me:

"I think I can survive. We'd manage all right. We'd manage all right. We've managed for - how old are we? Well, since 50 - say 50 years. We'd manage all right, don't worry about that, you know? You can't put your finger on it - but she'd struggle - your health's gotta suffer..."

Personally, I think Bobby and Grace would have a great deal of difficulty in managing. Although he says they have managed for fifty years, that was before Grace's stroke. Grace needs quite a bit of help getting washed and dressed which Bobby helps her with. But they have a big house which takes a lot of looking after, and as Bobby pointed out, it was always covered in cobwebs and dust outside. In addition, there is the shopping and cooking to think about. Bobby could go in to the nearest village to get supplies, but trying to get Grace

into a pick-up truck would be a real challenge. There would also be the extra work of trying to push Grace around in her wheelchair and do the shopping - fine if Grace could tolerate a shopping basket on her lap, but no good if they needed to use a trolley. Another option would be to leave Grace at home, cutting her off from a major source of social contact. I think that eventually, having to do the groceries would become a miserable chore for both of them. Having a home helper means that some of this burden is alleviated because the housework is done by the home help and so is no longer a worry to Grace and Bobby. Also, as pointed out to me by Grace, the home help is a great source of what is happening in the local community, and keeps Grace fully up to date. Although Grace might not get out as much as she used to, before her stroke, she still has plenty of contact with the outside world.

Similarly, Mary, an elderly Pakeha lady told me:

“Oh! I’d manage just fine! I’m not helpless you know...”

But Mary is 84 and she lives on her own. She lives about three miles from the nearest shop. She has no transport, and although her family are in contact with her, they all work, and all live out of the area, which makes taking her out quite difficult at times. She heats and cooks using a wood stove. She is not capable of chopping her own firewood, let alone going out to get it. Trips to get wood would have to be carefully organised. She would also probably have to buy ready chopped wood, which would make a big hole in her meagre pension. Having a home help alleviates this problem, as the home helper (amongst other things) sorts out all the wood for Mary, bringing it to the house, chopping it up, stacking it, and making sure that supplies are ample at all times. I believe that

without this help, Mary would have to have electricity installed, which she cannot afford, or move into the village which is three miles away, but which she does not consider home, or go and live with relatives out of the area completely.

Josie also believed she could manage successfully without a home help.

She told me:

“In my instance, the [home help service] is very very good because I’m slower than I used to be. Because I used to be able to do so much quickly and now it takes all day long to do what I do...We both forget now. We’ve got to that stage of life where we forget. We’ll think of something to do and then we’ll go to that place - and then we’ll think - ‘Well, what did we come here for?’ Very often, I can’t think what I was going to do...and my back is bad. But I could get along all right without [home help]. I could, really.” (Josie)

By her own admission, Josie is becoming slower and more forgetful. In this case, I think it is important to have someone popping in to make sure everything is all right at home. Her bad back means she cannot bend over, or down, so any sort of housework is difficult, as is a lot of food preparation. Josie also has a history of strokes and diabetes. Because of her strokes, she walks with a stick and doesn’t get out very much as it is too much effort for her. Her diabetes has affected her eye sight and she is nearly blind. Even if her husband were able to help with some of the chores, I think Josie would still find it very difficult indeed to manage with no outside help.

I think I was told these stories because people were trying to show they *could* cope with the demands of everyday life, even in the face of chronic illness. I found it interesting that there was little tendency to *overstate* a case. At the beginning of the study, I assumed (quite wrongly) that people would stress how

difficult their lives would be *without* a home help. I thought they would do this either for fear of losing their home help, or because they thought I would 'tell management'. However, it seems the overriding concern was to present to me, a stranger and outsider, a picture of normality and control, thereby keeping face and maintaining respectability (see also Cornwell 1984). This applied particularly to elderly Maori and Pakeha participants, male and female. It could perhaps be seen as one way of resisting a perception that I was placing them in a marginal position with what ever consequences this might have had. In contrast, the younger participants (all of whom are Pakeha women) were quite the opposite. They all emphasised how vital the home help service was to their general well-being, and presented a picture of how much the home help *was* needed.

6.5. DISCOURSES OF 'RACE', ILLNESS AND DISABILITY IN THE HOKIANGA.

"Dad- he had a very good Maori that he called Bible and he was a *good* Maori - but he had a disability. I can't - I don't know what the technical term was but he used to take a stroke every now and then and he - he was never violent - and my mother could handle him quite well she'd give him a cup of tea and he'd go and sit down in his room out the back there. But he was a *good* Maori."

"The slump babies. They were sad those slump babies. Their mother's used to feed them - I told you I think - they used to feed them on flour and water and I said to one mother one day, "Why don't you give them milk? You've got cows." But the milk all had to go to the dairy factory, you see, so that they could get the money for them. And the babies were just fed on this flour and water and they used to come in and - they - course the malnutrition was *terrible* for the little things and covered they were - the Maori itch - you know? And we had to put starch poultices on their heads - that'd be - their hair'd be growing through this awful great big crust with all the sores underneath. We'd

have to put starch poultices on to get the crust off so we could get down to their itch on their heads. *Oh!* The poor little things! And of course they were covered *all over*. All over their bodies. That was tar ointment.

I'll never forget one little girl - she *certainly* didn't have Maori itch...a little white girl from Waimamaku. We never - *never* touched a patient without a mask on or gloves. Poor little Maori babies - when they came in - I think they wondered what on earth they'd struck! All these awful looking creatures coming from out of the other world - coming down to get them. But it was - saying this - *not one of us* got Maori itch or *any* of those things..."

These are excerpts from Rawene Public Library Oral History Archives. The first story was recorded in 1991, when the historian recounting her tale was 81 years of age. The second story was also recorded in 1991, when that historian was 91. Clearly, historically, Maori were associated with certain illness conditions as well as certain temperaments. These comments are interesting because they support what I have already suggested in Chapter 2: that otherness in the form of 'race' and illness combine to produce what I call the racialisation of disease. By this I mean that certain diseases become stereotyped as those which affect specific 'races'.

This process still continues today. In the press, for example, headlines such as these are a daily occurrence: 'Smoking pushes up Maori heart deaths'⁴, 'Maori talks focus on way to beat violence'⁵, 'Dialysis perk for [Maori] elders'⁶, 'Funds boost for Maori health: grim statistics worry council'⁷, 'Maori Aids rate

⁴*New Zealand Herald*, March 8, 1996, Section One, p. 18.

⁵*New Zealand Herald*, March 29, 1996, Section One, p. 4.

⁶*New Zealand Herald*, December 14, 1995, Section One, p. 1.

⁷*New Zealand Herald*, June 20, 1996, Section One, p. 4.

blamed on poverty'⁸, 'Victim warns own people of disease devastation'⁹, 'More Maoris enter psychiatric hospitals'¹⁰. Official documents tell us that:

"The main causes of [Maori] hospitalisation are for pregnancy and childbirth injuries; respiratory diseases (pneumonia, influenza, asthma, chronic obstructive airways disease); and diabetes and its complications. There is a higher incidence rate for Maori in acute respiratory infections, lung cancer, and cancer of the cervix, acute rheumatic fever and chronic rheumatic heart disease, drug and alcohol dependence, sudden infant death syndrome, diabetes and its complications, hypertensive diseases, glue ear (otitis media with effusion), ill-health caused by tobacco smoking, skin infections and dental caries in children" (Shipley 1995).

Although the quotes above might well be 'accurate', it is the *constant* portrayal of Maori health in *negative* ways that becomes embedded in the popular imagination, creating stereotypes of Maori as diseased others. In turn, these conditions become 'Maori' conditions. In the Hokianga, major health problems for both Pakeha and Maori include diabetes, gout, heart disease and a high smoking prevalence (B. Allan, 1995, per. comm., 1996; HHET 1995). These conditions are often considered 'Maori' conditions, and indeed, they do affect more Maori than Pakeha in the Hokianga, both in real terms and proportionately. However, research within the Hokianga is beginning to show that Pakeha people's health status is much closer to Maori people in the Hokianga than Pakeha people elsewhere in New Zealand (J. Reinken, per. comm.). In addition, some conditions associated with Maori are less prevalent than in the rest of New Zealand - interesting for an area with 70% of its

⁸*New Zealand Herald*, 28 October 1994, Section One, p. 4.

⁹*New Zealand Herald*, 28 October 1994, Section One, p. 4

¹⁰*The Dominion*, 17 March 1994, p.1.

population claiming to be Maori. Examples include glue ear, a condition which affects children and hepatitis B. These conditions have lower rates because of good preventative care and high uptake of immunisation, respectively.

During my time in the Hokianga, I was interested to see what people thought about these kinds of issues and whether the same kind of process was occurring as that which was happening at the national scale. But I heard no stories that suggested this might be prevailing opinion in the Hokianga. In fact, I only managed to collect one story that was explicitly to do with 'race' and 'illness':

'She also said that she'd heard it said many a time that treatment in Hokianga depended "on the colour of your skin". I asked her to expand on this and she said that more effort was made with Maori people than with Pakeha. She gave me an example. She broke her ankle a while back and said "It wasn't treated right" but if her skin had been a different colour it might well have been. She claimed this was local prevailing opinion.' (Diary 2, 2.5.96.)

If this was local prevailing opinion, it was well hidden from me. So whilst I collected many stories on racial stereotyping in general, such as Josie's comments in the previous section, I was unsuccessful in collecting any that were to do with illness, apart from the one above. I think this was more to do with the way the interviews were structured than anything else. Because I was doing the evaluation study, I had to follow the topic guidelines (see Appendix 4) and these left no room for any comments about the racialisation of disease. In short, I was simply asking the wrong questions for getting at these issues. If I had had more time, I could have begun to probe this issue, but as they were, the interviews

were already quite long enough for most people, and I didn't want to outstay my welcome.

6.6. CONCLUSIONS.

In this chapter I have considered very different discourses, narratives and themes within the context of home help in the Hokianga. Taking as its starting point the articulation of local experience, and by using narrative accounts as the central subject matter, I have tried to add extra dimensions to areas of personal interest. These are (i) the practical uses of narrative, in this case, supplementing the formal evaluation of the Regional Health Authority; (ii) the beginnings of a more contextualized and refined medical geography; through (iii) an attempt at theorised action research.

In trying to do research that produces a more nuanced medical geography, I have examined whether these narratives, situated as they are within wider, criss-crossing discourses, are marginalised or even marginalising others. From my experience and research evidence from the Hokianga, these narratives are marginalised at the national rather than the local level. As a result, in this case, geographies of exclusion arise at the national rather than local scale. Within the Hokianga, the majority of people are in a similar position, facing the daily grind of simply getting by. At a national level, this area and these people are portrayed as different to the rest of New Zealand, draining the country's resources and patience. Discourses of the Hokianga as marginalised and other are clearly portrayed in national magazines such as *North and South*. In turn, these ideas take hold in the popular imagination, so that victim blaming does

indeed take on the appearance of a national sport (Consedine 1989, see footnote 15, Chapter 3).

These ideas feed into health. It is often perceived that rural health services are more expensive to provide than urban, and this tends to support the case for closure of small scale facilities and greater centralisation of services. However, the Hokianga scheme costs only \$800 per person per year, as opposed to the average cost for New Zealand overall of \$1200 per person (B. Allan, per. comm.). It is also widely perceived that Maori health status lags behind Pakeha. Research in the Hokianga suggests, however, that the health status of resident Pakeha is much closer to Maori residents than it is to Pakeha outside the Hokianga (J. Reinken, per. comm.). Once again, it is the collective experience of the Hokianga that comes to the fore, highlighting how marginalisation and otherness can occur at a group level. In addition, marginalisation and otherness occurs at an individual level. This and the combination of group and individual levels serve to further complicate the experience of chronic illness and the home help story in the Hokianga. In the next chapter, I turn now to these issues.

CHAPTER 7. DISCOURSES OF HOME HELP 2: IDENTITY, DIFFERENCE, OTHERNESS.

“When you’re old and there’s nothing more they can do - they just brush you aside...” (Mrs Blumer)

7.1. INTRODUCTION.

In Chapter 2 I suggested that otherness occurred at two levels: individual and group. At a group level, stereotypical notions of ‘people groups’ are formed, and group identity becomes othered as a result. In Chapter 6, I scrutinised narratives of home help that refer to marginalisation and otherness at a *group* level. They were narratives of: (i) rurality; (ii) disability; and (iii) ‘race’/ethnicity. This chapter examines narratives of home help that refer to forms of difference at an *individual* level. These differences can greatly influence a person’s identity and subjectivity; they might even spoil or ‘other’ an identity in some way. Moreover, as will be seen, differences are not mutually exclusive: they are tightly intertwined and therefore, in poststructural terms, thoroughly intertextual. The grouping of narratives not only examines the diversity of individual subject positions, but also the wider context of shared experiences. At both individual and group levels (which are admittedly arbitrary and with fuzzy borders), these narratives are important, because they suggest ways in which the biomedical model on its own is an inadequate explanation for ill-health. For example, biomedicine concentrates mostly on the *disease* status of a person. In contrast, I see these narratives as circulating around *people*; and around certain aspects of their shared and individual identities, for example their ‘race’ or disabilities.

As outlined in Chapter 4, the community trust, Hokianga Health, wanted to undertake a qualitative evaluation of their home help service, in the belief it would give them another perspective to the narratives of policy. The questions they were interested in revolved around quality, quantity, efficiency and effectiveness - but from the perspective of those involved with the service. Basically, what did people '*out there*' think of the service and could it be improved? The previous year, (1995) the Regional Health Authority had commissioned an independent audit of Hokianga's Home Support Service (of which home help is a part). This was to ensure that Hokianga Health was complying with the Regional Health Authority's policy on Home Support Services. The concerns of both audit and policy were similar in that they were framed around notions of quality, quantity, efficiency and effectiveness. The striking thing about these policies was a sole reliance on quantifiable measures, such as how many people receive home help; the average cost per hour of service; how many complaints there have been and how many clients had left the service. Regional Health Authority policy, and the audit as a subset of that, left no space for qualitative measures of success or failure, nor was there any acknowledgement that at some point it might be useful to involve 'consumer' opinion. Because of this, Regional Health Policy is only a 'partial story', and is open to criticism¹. This story, however, could be considerably enhanced by

¹Instead of being viewed as more or less biased sources of data, official documents should be treated as social products (Hammersley and Atkinson 1995: 168). This means they must be carefully examined, not relied on uncritically as a research resource (ibid.). Although I agree with Hammersley and Atkinson's argument, in the context of this piece of research, it was not necessary to critique Regional Health Policy and audit, as I was trying to find out whether the home help service was meeting their requirements.

supplementing it with narratives from those who experience the service on a daily basis. In exploring narratives of home help that are circulating within the Hokianga, I consider not only their differences, but also how they might be incorporated into meaningful health policy and planning initiatives. The aim, therefore, is to reflect on local knowledge, and consider how it might be put to practical use in a community setting. In order to interpret the stories, I have examined the material in the same way as the previous chapter, that is by 'race'/ethnicity, by age and by gender.

7.2. NARRATIVES OF IDENTITY, SUBJECTIVITY AND HOME HELP.

Identity, according to Stuart Hall, is 'formed at the unstable point where the "unspeakable" stories of subjectivity meet the narratives of history, of a culture' (1987: 44, quoted in Chambers 1994: 25). It is the '...interface between subjective positions and social and cultural situations' (Woodward 1997:1). Who, and what we are is not inevitably choice, but often determined by factors beyond our control. In large part, our identities are dependent on our social and cultural situations. The conditions of our selfhood, and how we behave, are structured through material contexts. The experience of home help is but one of these material contexts, and is therefore more or less implicated in issues of identity. Stories of health, illness, and the experience of home help, are inextricably linked with notions of identity, because they all impact on an individual's subjectivity. Home help is implicated in the construction of identity by transforming a person into a recipient, or a giver, of home help.

Unsurprisingly then, in collecting local narratives of home help, I frequently encountered such narratives of identity and subjectivity.

On reading the stories of home help, certain key features emerged as important for different groups of people. For Maori clients, particularly elderly ones, these were (i) the preference of a *whanau*/family member to be the care giver; (ii) issues of privacy and dignity, specifically laundry practices and (iii) the support and friendship derived from home helpers. For Pakeha clients, the important issues were (i) that outside work was not included in the contract and (ii) the support and friendship derived from the service. However, there was little distinction between Maori and Pakeha home helps' narratives. Both focused on (i) the friendship aspect; and (ii) the employment aspect.

Family/*whanau* issues.

Raymond Williams (1988: 133-134) has traced a history of ideas about the family. Family as lineage, household, large- and small-kin groups have all been prevalent at different times and places. He argues that there have been major historical revisions of the concept, and that contemporary families have inherited some of the previous complexities. These radically changing definitions of primary relationships are crucial for identity formation. Western notions of the family stem from the development of mid-nineteenth century capitalism, where the family became an isolated economic unit, (ibid.). It is thus wage-labour, and who that wage supports, that defined the family unit and gave it its security. These ideas were taken to New Zealand with the colonists, and remain the 'norm' for Pakeha. On the other hand, for Maori, the family, kinship

ties, and the extended family give a feeling of belonging, value and security (Pere 1991: 26). Knowledge of genealogical ties is vital, in order to identify with heritage. For Maori, the family (whether nuclear, extended or whatever) that does something together enables each member to feel they have a niche and is important. These families engender pride, unity and a real sense of belonging (ibid.). The concept of family in Maori eyes is therefore more to do with support in terms of belonging, than capitalism, wage labour, and financial support. In the Maori health model, *Te Wheke* discussed in Chapter 3, the head of the octopus represents the child and her family; each tentacle represents a dimension that requires certain things to help give sustenance to the whole. In Maori tradition, a person's head is a most sacred part of the body. It is therefore clear that the concept of the family is held in exceptional regard.

Sarah, my 'key informant' and Hine, an elderly Maori lady explained to me why Maori tend to prefer *whanau*, for both personal and domestic duties. It is a typical account of why *whanau* members are usually preferred as home helpers and one of but many acquired during the study:

Sarah: "You'll find with a lot of our old people - they gotta lot of personal things that belonged to an ancestor. You know like - and that's more personal to them than their own stuff."

Hine: "than their own bodies."

Sarah: "Than their very own. And they don't like strangers to touch stuff - to them that's personal. They don't like strangers around"

Hine: "their privates. It's more private than your body, put it that way".

Sarah: "And I feel that's one of the reasons they...would prefer *whanau* because 9 out of 10 - the *whanau* knows what - well, we call it a *taonga*...and family members know of it. And are wary of it...coz they know what it means."

Hine: "My mate - specially my mate - he's very wary of those. You know he's one of those...you know, he's very private my husband...I don't know what he's doing, to be truthful...that's why I don't like - don't let anybody in our room. Making his bed, his clothes and things like that? Only his children..."

Pearl is the home helper for her father-in-law. She is originally from the King Country, but moved up to the Hokianga through her marriage 12 years ago. She has also been a home help in the King Country, and she says that working in the Hokianga is the same as working in the King Country. She and her *whanau* live in a tiny settlement of approximately 20 houses. She says the hamlet is growing, but mostly because of people (*whanau*) returning. Everybody is related to each other somehow. She told me that:

"It's a basically Maori population round here - they should *know* that the old people like to have their own looking after them...You'll find with a lot of old Maori people - they don't like outsiders - they don't like people nosing around - you know, they're very private...they told the nurse they won't have anyone else - you know - you find that, the old Maori people - don't like outsiders...they're a bit proud, my mother- and father-in-law. They don't like people coming in to them. My father-in-law especially. He doesn't like people going into his house that he doesn't know. So that was why it had to be me or no one at all. It's just how Maori are, eh? They're proud people and they just don't like - maybe their home is not up to what other people's houses are, and they feel a bit funny when you get outsiders. They'd rather have their own coz they know their own knows. They know what they're like. I suppose people have got little - I dunno what you'd call it - little things like my father-in-law he has a - a *mimi* bucket in his room coz the toilet's too far? [and outside] Especially at night time - You know and when it's raining and the wind is blowing - you know to have a stranger come in there and see it - you know - you'd feel a bit embarrassed."

These differences impact on the home help service in several ways, most notably that Maori consistently request family members to be home helps, whereas Pakeha do so much less frequently. Nearly all the clients, both Maori and Pakeha, talked about how they got their care giver. The issue of choosing a care giver is closely related to a person's preference for *whanau*/family to provide that care. Just over half of them chose their own care giver, and the Community Health Nurse chose for the others. It was notable that most Pakeha people had their home help chosen for them, whereas Maori people tended to chose (insisted on having) their own. The issue of choosing a care giver is closely related to a person's preference for *whanau*/family to provide that care. Hauora Hokianga's policy on this is that family can do personal care, but not domestic duties. This policy is not rigidly enforced, because personal care and domestic duties are lumped together for many clients, and, in the end, client preference is the deciding factor. This policy is in place, though, to protect the client from a potentially awkward situation if the relative does not fulfil their assigned duties. If the care giver is unrelated, the client-care giver relationship is different, it is easier to monitor the situation, and it is assumed that it is easier to complain about an unrelated person. Of the 16 clients who chose their own home helper, 5 were Pakeha. None of their home helpers were related to them. 11 Maori clients chose their own care giver. 4 were blood relatives (a granddaughter, two nieces and a daughter), two were related by marriage (daughters-in-law), one was a "very distant relative", three were not related and one client said she was related to the care giver, (although the care giver disputed this!).

In this study, the family as a source of comfort, security and identity, and as a home helper option appeared to be less important to Pakeha. In addition to Williams' suggestion above, I would add a number of reasons for this. First, many of the elderly Pakeha people I talked with had retired into the area, and had no family nearby. This meant that when it came to home help, they had no option but to have an unrelated care giver. They therefore tended to leave it up to the Community Health Nurse to sort one out. Second, as Belinda, one of the Community Health Nurses explained, Maori and Pakeha expectations and traditions in old age are very different:

“[Maori] take it as their responsibility. In European families - to a much less extent. It works on a different level. And it works on a different level from both the expectations of the elderly and the families. The - as you become elderly in the Maori culture, you gain *mana* and family are expected to come home and care for you - that's part of how it works. And you can actually ask for who you want to have and each person has their specific person that they want to have as their care giver. Whereas - for - and the family expect to do that. And - whereas with the Pakeha - Pakeha want to care for their elderly, and provide care, a lot - yet - not all of them would want to have their elderly at - in their home. Many a home's not been suitable for that. The expectation is a lot of elderly feel that they don't want to live with their families and so that makes it harder for it to happen and they usually find and provide care for - rest homes and things. And for a lot of Pakeha elderly they would prefer that, being amongst a group of people their own age than with family with young children and so - it's different expectations - “I don't want to be a burden on the family,” you know? And...they just won't go to family. I guess the other thing with the Maori is that - the need for space - that personal space is not the same as for Pakeha and the elderly are more likely - not all of them - but a lot of them are quite happy to travel between the different family members and spend time with the different families in the different places. And so, therefore, - it doesn't matter - they're at home when they're with family wherever - you know? Whereas - a lot of Pakeha families - that doesn't kind of work for...? I know that some - some have a sort of rotation but it doesn't work as fluently as it does for the Maori.”

Yet there were some people who definitely did *not* want a relative to be their home help. Four Maori and two Pakeha decided that they would prefer not to have a related care giver. There were varying reasons for this. The two Pakeha and two of the Maori clients had no family that could have filled that role. The other two Maori clients, Ruth and Wiri were adamant they didn't want close family members being their care givers, but for different reasons. Ruth, the only 'young' Maori client in the study told me:

“Well, put it this way - yeah, I wouldn't mind the *whanau* as long as it's not my kids - I mean, not my baby - not my daughter eh? I only say that coz we'd spend all day damn well swearing at one another!”

Wiri, one of the five elderly Maori men in the study told me:

“Ah no! They're bloody humbugs you know! Bloody humbugs! They'd walk in the door and “Good Day, Good morning, hooray!” Na! I don't want them. No good. Oh early in the morning - they'll have to mow the door down and “Hey, how are you - you're all right. OK.” And they'd be gone!...They want that money. Once they've got that money...and they're off!”

The general feeling amongst clients, staff and some Community Health Nurses was that people should be allowed to choose their own care giver, regardless of whether that care was domestic or personal. Although many Maori understood and were sympathetic to the reasoning behind the *whanau*/family policy, comments were often framed along the lines of, 'I heard of it happening in another family, but my family wouldn't do that'. Winnie exemplifies prevailing opinion amongst Maori people, whether old, young, male or female:

“I think that’s fair enough [*whanau* policy]. Yeah, coz there must be people there that take advantage of it. And abuse it. But then again...I’d like them to keep an open mind about it too.”

What do these stories tell us? Firstly, that *whanau* means different things in different contexts. In some cases, it means direct bloodlines - children and *mokopuna* (grandchildren). In others, it means a close member of the extended family, in the sense of familiarity and love, but not necessarily blood-related. Thus a niece or a daughter-in-law would be considered *whanau* in some contexts. The reason for this is that *whanau* in Maori is both a verb ‘to be born’ or ‘to bear a child’, and a noun referring to (extended) family. In the context of home help, this sets up a situation of compromises which are acceptable to some, but not to others. Official policy tends to define *whanau* in terms of the former definition, but it can also be defined it in terms of the latter. If a client can find a *whanau* member who is not a direct descendent, they can be their home help. For many, this is a satisfactory solution to the problem of getting a family member in. In addition, it is often used as an excuse by those who prefer not to have close relatives as home helps. However, for others, who want their children or *mokopuna* to be their home help, it remains, an insoluble failure of the system.

The evidence suggests that although two did not want *whanau* to be their care-givers, most Maori people did. This raises a problem for Hokianga Health, because neither Regional Health Policy nor Hokianga Health Policy allow relatives to be a persons’s home help. The official policies are that family can do personal care (hygiene and grooming), but *not* domestic duties. The rationale behind the policy is that if the care giver is unrelated, the client-care giver

relationship is different, monitoring the service is easier, and it is less traumatic to complain about an unrelated person. The policy is in place to protect vulnerable clients from a potentially awkward situation, for example, if the relative does not fulfil their assigned duties. However, it is open to criticism because it assumes that a related carer will *invariably* carry out their personal duties, whereas they *might* not always do the housework. Although I did not come across any actual cases, what if a related carer neglects the personal hygiene and grooming side of a client's care? It is not impossible that this could happen.

In my experience, therefore, home help practices did not always match dominant discourses. The stories above suggest that hegemonic discourses, in the form of official policies, run directly counter to what many clients and care-givers believe is vital for health and well-being. However, at a local level, (and in a very discrete manner) Hokianga Health enforce neither Regional Health nor their own policy strictly. This is because personal care and domestic duties are often amalgamated, and, in the end, client preference is often the deciding factor. This is perhaps an example where supposed dominant discourses are not necessarily matched by practices: evidence that they can be undermined by relatively weak but persistent discourses and practices. This suggests to me, at least, that those subordinate discourses are not as weak or ineffectual as I had previously supposed.

What are the health and policy planning implications of this? I brought up the discrepancy at a meeting with the Chief Executive Officer of Hokianga Health Enterprise Trust. My diary entry for the 2nd July 1996 reads thus:

“Talking to B about policy narratives. She wondered if policy actually needed changing because the narratives of policy don’t match up to the narratives of local. Especially with *whanau* - ? need to change policy? B wondered if it actually needed to be made more flexible to allow *whanau*...”

In the event, policy was left as it was. This was because most people who wanted a family member could find *whanau* that were neither children nor *mokopuna*. They were therefore acceptable as home helps under the terms of current policy. But alerting the policy makers to the differences between policy and lay preferences means that this issue may well be a subject for review and change in the future, and I was assured that Hokianga Health Enterprise Trust would discuss this matter with the Regional Health Authority at a future date.

Dignity, privacy and the question of laundry.

Another parallel between policy and local discourses revolved around dignity and privacy. As part of the evaluation, clients outlined the jobs that their home helps did for them. Most of these were everyday, mundane tasks such as vacuuming, doing dishes, dusting and mopping floors. However, one task generated a lot of unexpected discussion from Maori participants. This was the issue of laundry. In the study, laundry was an instance where dignity and privacy for Maori are paramount. However, it also posed some interesting dilemmas. It may seem a petty subject to be writing about, but if the Philosophy of Home Support Services is to be taken seriously, then laundry becomes really quite significant. It states that:

“Support services are instigated that reflect the needs and allow the client to make decisions that maintain their cultural, social and physical norms with dignity.” (HHET 1995: 19)

In the beginning, I was deeply uncomfortable about talking through issues of laundry. I was dealing predominantly with a different generation of people, who had had radically different upbringings and life experiences from me. These ladies were *kuia*; the elderly women of the tribe. With *kuia* status comes many things, in particular, the eligibility to become a candidate for special priestly duties and the unique role of welcoming visitors onto the marae. They are held in high esteem. I wasn't too sure that they would welcome the prospect of a Pakeha girl picking up on their most personal activities. My key informant Sarah reassured me. She said that because the *kuia* had finished their child-bearing years, they were able to talk about these issues with less discomfort than a younger woman would, because, as she put it, "They were past all that".

In addition, this was one of the instances where the Maori language, or *te Reo* proved invaluable. Questions of washing underwear and personal clothing would be regarded as impolite if asked in English, but can apparently be asked in Maori in all-encompassing terms. The fact that Sarah was a highly respected member of the Maori community meant that she could ask these questions without causing undue discomfort or humiliation. This, and her translations, lessened the potential for cultural misunderstandings to occur.

In Maori culture, a persons' body, particularly women's bodies, are very private and personal affairs; a theme I pursue at length in the next chapter. Because it is perceived as an extension of their body, laundry, especially underwear is also a private and personal affair. Maori women (and men) usually prefer to wash their own underwear, rather than let their home helpers do it. This

is one of the main reasons that Maori prefer *whanau* as home helpers. The majority of Maori people we spoke to said they would rather *whanau* rather than a stranger to do household chores and this was especially true when it came to washing their clothes. As Hine said:

“Even when it comes to personal things - I do it myself. Coz I don't want anybody doing my - you know - when you get older, you get all sorts of complaints. Well I don't let any of them - I do my own personals. I do it my own...with my immediate family, well, I don't mind them - they just put the washing in and that's it. I don't mind them...”

Likewise, Kare, a sixty six year old Maori lady, preferred *whanau* to help with laundry:

“Like er, with me, with my clothes to be washed, - I'd sooner my daughter did it [than the home help]. My daughter would be really good. It's not a husband's place to do washing - well - in a Maori way anyway. My undies and my tights I don't give my husband to go and do those. If I'm in the shower, I'll do it myself. He doesn't know I've got it in there...and my rags, you know [she suffers from stress incontinence]. With my daughter, well I can just give it to her and she'll do it. No, no, I *never* got my home help to do it. Not those private parts. I got my daughter-in-law to do it. When she comes - I ring her up - otherwise Dad'd have to do it. I don't want Dad to do it. I don't want to see what's - you know. Although he's my husband, but he's never seen that sort of thing...”

The home helpers were sympathetic to this preference. Penny, a Maori home help in her early thirties, talking about her unrelated elderly Maori lady client, said:

“I know that one of her biggest things was her clothes...washing their clothes. They don't like their underclothes things mixed up with - like their tea-towels and their towels and things with their socks...tea towels on their own. And personal body stuff on

their own. No. Like your body stuff always totally different from - you wouldn't use a tea towel to wipe yourself down with....[she] likes to do her own personal washing coz she's a Maori as well."

And Pearl, Maori home helper for her in-laws agreed:

"[*whanau* should be allowed as home helps because] "...they feel comfortable with that person - they're not embarrassed if their home is in a mess and - coz you've got to do washing as well - and - well I think older people can get a big thing - its shameful for them to have an outsider to see their dirty clothes? So its better for family - you know - see even with me, their personal things - she'll do them herself."

Logistical reasons meant that in the study, Pakeha clients were visited first. None brought up the idea of laundry. I had no idea it was going to become such an issue in the later stages of the research, and this meant, unfortunately that I did not pursue it at the time. Time constraints towards the end of the study meant I was not able to revisit Pakeha people, there would have been simply too many people for me to re-interview. Therefore the study has no data on Pakeha preferences about laundry. This is problematic because there is no documented data to support or refute the claim that laundry preferences might be culturally influenced. However, unlike Pakeha, Maori clients often brought up this subject quite spontaneously. Those who didn't were gently probed on the issue, by Sarah. Unless it is even more taboo to speak about laundry in Pakeha culture, (and I don't think it is), the implication is that it was less of an issue for Pakeha. Therefore I believe that the issue of laundry is culturally influenced, largely because it is seen as an extension of one's body in Maori culture. Although there is certainly modesty about personal laundry, I do not believe that Pakeha see laundry in quite the same way. In terms of policy and planning issues, this aspect of home help is similar to what I have already argued above. *Whanau* (however

defined) should be allowed as home helpers because of these very personal and potentially embarrassing affairs.

Gardens and outside jobs.

The contract of Home Support Services employees does not permit outside work, and this issue was raised consistently by elderly Pakeha clients. In fact, whereas the most common concern of Maori seemed to be family/*whanau* issues, for Pakeha it was the garden. This to them was of paramount importance. Although clients and care givers know it is not covered by the formal work contract, this work was being undertaken by a third of home helps, according to their clients. For the clients, it is important. For many, to sit by the window day after day, watching their garden turn into wilderness was quite distressing. Josie, for example, bemoaned her weedy garden and told me that:

“Home help doesn’t deal with gardening and that’s probably where there’s a bit of a lack...home helpers are not supposed to help with the gardening and I think that’s regrettable. The lady who comes to me- at the moment- only does inside the home. I have been hesitating whether to ask her to do a bit of gardening. [My friend’s] lady helps her in the garden which is wonderful...and I’ve got to the stage where I don’t do the garden anymore. I think that would be a really good thing to add - some gardening...I personally think it would be wonderful if people could do that. For those that need it...”

This concern with weeds and disorder in the garden recalls my earlier discussion on dirt and matter out of place. In Chapter 2 I described how Mary Douglas has shown, through the example of dirt, how rituals extend to all aspects of every day life. She suggests that what we perceive as dirt is a function of our ideas about hygiene and respect for social conventions. Dirt offends

against order, and our efforts to remove it are attempts to organise and purify the environment. I would argue that for many of the elderly Pakeha clients I spoke with, this would apply to weeds in the garden as well. A weedy garden indicates a lack of control over one's life and the inability to create order in the garden affects peoples identity, because it suggests they are no longer in control. This idea of a weedy garden, and a lack of control was much more apparent in Pakeha stories than Maori, suggesting that it was more important for Pakeha to keep this kind of apparent control than Maori.

Friendship and social well-being.

Companionship and support is an integral part of emotional and mental well being. A British study found that the most significant problem for patients was social and emotional well being, where "...contact with services was often limited, so little more was possible than bare physical maintenance, rather than empowering and supportive social care." (Richardson and Pearson 1995:279). In contrast, this study has found the opposite. In Hokianga, home help is essentially a social interaction where the boundaries between job and friendship become incredibly blurred. This defuses power differentials between a client and a worker. According to many care givers, there *is* time in the work relationship for these aspects of care to be nurtured and developed. Although many of care givers said they had enough time to do their tasks, they also stayed over their hours, to do the 'little extras' that mean so much to the clients. It is these extras which add so much to the well being of clients. Further evidence for 'social well-being' lies in the narratives of friendship which dominated our conversations. This was seen by many as *the* most important part of the home

help service. The benefits of this companionship are hard to quantify but given their frequent reference, it was obviously perceived as really important by *all* participants in the study, regardless of ethnicity, age, gender and their position within the home help set-up. Elizabeth, the Community Health Nurse highlighted this:

“Companionship. That’s a very important aspect of it. That when they’re living in isolation, to have somebody going in...its through that that the care goes beyond the bounds of the time set. And - I guess that’s all part of community building too. Bringing people together that might not otherwise get together, getting people out of their homes to care for others. That would happen to a certain extent but not on such a regular basis [without home help].”

Meri, a Maori lady in her late sixties, has difficulties in managing at home because of her arthritis. Her experience of home help is as much about the physical contact with a person as it is about the psychological support:

“Having someone there with me that I can hold on to. We usually hug each other - we’re so happy to see each other on the day she comes...I’ve never been near to a person like that before...I’m blessed! She’s *such* a good friend. I just couldn’t manage without her - it’s not the cleaning, it’s the company...”

Josie, an elderly Pakeha lady who does not get out much and who is nearly blind agreed:

[The service] “...gives company. A lot of people living on the back blocks don’t get a lot of company. But to think of someone coming in - even if they don’t gossip - someone different to talk to. So I think that someone comes in and speaks sprightly to them - so perhaps it can help with suicide, it can help with company, it can help with peace of mind...”

This relationship is not one sided. Carers also mentioned how important the friendship was to them, and the extras they took on. For example, Kate is Meri's home helper. She is a Pakeha lady in her late fifties, who has been in the Hokianga for about ten years:

“I think sitting and chatting is one of the most important parts of the job...It sort of makes you relaxed when you can just sit and have a good talk. It should be number one on the job list...I told [her] at the early stage that if [she] needed company, or someone to talk to, that's just as important as cleaning. And while [she] was sick to start with, I would use probably a quarter of the time with her talking and sharing...and there's a real closeness grew out of that, a real loving grew out of that...you can be their only contact - one of their main contacts with the outside world...OK, the cleaning is a good thing health wise, but mental health is almost as important as physical...they can become so isolated...”

And Penny, a Maori home helper who has both Pakeha and Maori clients agreed. Referring to both her Maori and Pakeha clients, she told me that:

“They really look forward to it, eh. I mean, they're home all night, by themselves, no one to talk to. You know? And when someone shows up and wants to stay an extra hour - just to yarn with them about anything - elderly people have got so much to tell us young people...I like hearing the knowledge that they have of their experiences. And I love that...”

Every participant in this study, whether client or care giver, young or old, Maori or Pakeha, male or female, talked about the companionship side of the service. To their credit, Hauora Hokianga are well aware of the influence of social interactions on people's health. This is explicitly recognised in the care plan/task list that is set out for each home help arrangement (see Appendix 2). However, at policy level, there is a tendency for discourses of social care to avoid the issue of social well-being, of which I would argue companionship is an

integral part. This matter goes unstated at both the regional and local level. I think this is so for several reasons. The introduction of commercial and market mechanisms fundamentally changes the relationship and relations between 'customer' and home helper, despite the success of a home help service in large part resting upon these crucial social relationships. The tendency of social care services to view shopping and cleaning as minimal basic tasks undermines this concept of 'social well-being'. As Richardson and Pearson point out (1994: 284-285), to 'see basic human needs in solely physiological terms...is to deny the importance of social participation and maintaining established roles'.

Policy and audits are concerned with numbers, throughputs and outcomes. These are relatively easy to measure and compare within and across areas. Companionship might be the bedrock of a person's well being, but how do you measure it? How can you compare it? What would be the defining criteria and guidelines for 'high quality' companionship? How could it be incorporated into a policy? As well as these problems, it somehow doesn't look very scientific, when one is assessing quantity, efficiency, service structures, record keeping and the like. Policy makers hope 'it just happens'. And in many cases it does. But it is regretful that it is not acknowledged somewhere, and somehow, in official policy.

Different accounts draw on different resources, for example, imagined geographies, material circumstances, expectations and life experiences. In turn these result in the production of different discourses. Different discourses have different plots and this can be seen through the prioritisation information in the narratives. When thinking about policy, notions of efficiency and effectiveness

are seen as important. From a lay point of view, for both Maori and Pakeha, it is friendship and social well-being that are paramount. The contradictions between policy's 'customer' and the reality of companionship can be seen by the differing narratives and their reliance on different terminologies. A friendship isn't usually based on a customer-worker relationship. The narratives of friendship have given Hokianga Health an important insight into a side of the home help story that no amount of measures as currently practised by the Regional Health Authority, or their auditors could have provided. And as I have argued already, it is *this* relationship that is so vital to a person's well being.

Employment.

For care givers, the two most important aspects of the home help situation were the fact that it provided company and social support for both client and care giver, and that it gave them a job. These two topics were brought up equally by both Maori and Pakeha care givers.

For example, Penny is a Maori home helper in her mid-thirties. She told me that:

"I like working with aged people - I like that contact...I like learning the knowledge that they have - their experiences. I love that. I guess it's nice for me to have an income for myself - I mean it's nothing outstanding, but it keeps me afloat..."

And Kate, a Pakeha in her late fifties and home helper to Meri said:

"And it's not only good for the people you help, it's good for the people going in because it means you've gotta job. Coz there's not many jobs in this area. And it means you can get a little bit ahead. Like if you're on a benefit - for us - we can actually save a little bit of

money - it helps the people you are helping and it helps the people going in and doing the work.”

In different ways, these comments highlight the important point that Home Support Services serve more than just the client. Even though they might be seen as the central character in the set up, the service is alleviating some of the stress placed on many Hokianga families - through either taking some of the work load off relatives, or by providing an important source of employment, albeit mostly part time. So the fact that the above comments talk about family, community and work is important, because it shows that people have an appreciation of Home Support Services that goes far beyond the client and the care giver. This is, in my opinion, one of the service’s greatest strengths.

7.3. CONCLUSIONS.

This chapter has been concerned directly with stories of home help in the Hokianga. From an evaluation viewpoint and the participant’s perspectives, the stories suggest several things. Firstly, that illness is a social as well as a physical experience. Participants highlighted this in their stories of home help, particularly those of family, companionship and work. Secondly, the stories display cultural particulars and the kinds of stories told, as well as their subject matter reflect cultural presuppositions and values (see also Silverman 1995: 114; Toolan 1988: 164). Thirdly, the stories are further complicated by ethnicity, gender and age. Fourthly, what gets produced in narrative is a political strategy and can be a tool for challenging the status quo. Stories always come with ‘baggage’ and it is important to think about the ‘what’ of the story and the ‘why’ and ‘how’ of its presentation. As such, the politics of reproduction should be

taken into account. For example, I believe that many of these stories were told to me with the purpose of initiating change in the home help set up. (I was evaluating it, after all!) The mechanisms of translating an impersonal policy into a meaningful personalised service places demands of flexibility and creativity at ground level. This means that discourses do not always match practices, which to me, suggests dominant discourses are sometimes resisted or negotiated in various ways. The example I have given here in this chapter is that of *whanau*/family being allowed to be a home helper for a relative. This exemplifies one way in which narrative can be used as way of interrogating the issues, and confirms their importance in changing the status quo. Even though policy was not ultimately, at least these stories alerted Hokianga Health to the presence of a potential gap in the home help service.

In this chapter I have described some of the discourses of home help amongst Maori and Pakeha in the Hokianga. In it I have tried to be sensitive to difference as well as sensitive to place. By focusing on certain narratives in relation to difference, identity and otherness, I have suggested that Maori and Pakeha have both diverse *and* similar priorities in the realm of home help. The next Chapter takes yet another group of stories collected from the home help evaluation, but examines them within the wider context of Aotearoa/New Zealand. These stories hinge around notions of the body, difference and identity, both at the individual and group level. They offer glimpses (and sometimes more) of the different facets of embodiment seen whilst undertaking the home help evaluation. Doing this will enable me to further explore socio-cultural dimensions of health and illness, and to consider how these aspects are played out on real bodies in real life.

CHAPTER 8. DISCOURSES OF HOME HELP 3: THE BODY.

8.1. INTRODUCTION.

Addressing questions about the nature of ill health means exploring the nature of the body, although until recently, the significance of the body in social research has been underestimated (Cranny-Francis 1995; McDowell and Sharp 1997; Pile and Thrift 1995; Turner 1996). The body was seen as an unproblematic, real biological thing; a universal phenomenon, regardless of the social and historical context within which it was situated (Nettleton 1995: 104; Turner 1992, 1995, 1996;). However, the impact of social constructionism (including the critique of biomedicine), the advent of new ways of thinking and seeing the world (for example, postmodernism and poststructuralism), and the rise of various social movements (for example, feminism) have forced a reassessment and incorporation of bodies in social research (Bordo 1993; Butler 1990; Cartwright 1995; Falk 1994; Featherstone et al 1991; Grosz 1994; Haraway 1991; Nast and Pile 1998; Ussher 1989). As a result, the last ten years has witnessed a vast outpouring of publications on the body. Notions of the body have begun to be problematised, examined and included, to the extent that now, studies of it are currently 'in vogue' (Cream 1995: 32, quoted in Parr 1998: 28). In particular, theoreticians of feminism, poststructuralism, and consumer culture have all turned their attention towards the role of the body, focusing on (i) its constitution in human subjectivity (Bourdieu 1984; Foucault 1967, 1976, 1981; Frank 1990); (ii) in elite and popular discourses (Benson 1997); and (iii) how perceptions of our own bodies are culturally controlled (Benson 1997; Bordo 1990, 1993; Martin 1990). There are common themes running through these

literatures, for example, the body and sexuality (for example, Butler 1993; Foucault 1981; Jacobus et al 1990; Lancaster and di Leonardo 1997; Segal 1997); body shape as influenced by discourses of diet (Bordo 1993; Falk 1994; Turner 1982, 1982a; 1992); and the body as shaped by exercise (Bourdieu 1978; Dutton 1995; Featherstone 1982, 1987).

In Chapter 2, I outlined some of the main recent developments in the sociology of the body. In this chapter, I build on those literatures, by considering the work of other writers whose work is also important for this thesis. They are important because they have all made fundamental contributions to our understandings of the body at both individual and societal levels. Throughout the chapter, I draw on specific strands of their work, and consider how project participants conceptualised and related to their bodies. Did sickness or disability alter these perceptions? And were these judgements culturally influenced? Approaching the chapter in this way enables me to address some of the issues I have already highlighted, in particular, the need for contextualised theory to accommodate the particular circumstances of different regions; and that the politics of research must be continuously taken into account. In addition, I hope that this chapter (indeed, the whole thesis) contributes towards a more theorised and nuanced medical geography, as envisaged in Chapter 1.

I am interested in the body because it is implicated in discourses of otherness and marginalisation. Dominant discourse defines others in terms of bodily characteristics, and constructs these bodies as ugly, dirty, defiled, impure, contaminated, or sick (Young 1997; see also Douglas 1966). In Young's (1997) version of cultural imperialism, oppression is experienced through a multitude

of general forms (for example, 'race', gender, illness), where a group is invisible at the same time that it is marked out and stereotyped. When a dominant culture defines some groups as different, as the other, the members of those groups are imprisoned in their bodies. Young argues further that others are then defined as nothing but their bodies and that they are imprisoned in an undesirable body, whereas dominant groups occupy an unmarked neutral universal and disembodied position which is masculine and white by default (1997: 219-220). Culturally imperialist groups project their own values, experience, and perspective as normative and universal. Victims of cultural imperialism are thereby rendered invisible as subjects, persons with their own perspective and group-specific experience and interests. At the same time they are marked out, frozen into a being marked as other, deviant in relation to the dominant norm. The dominant groups need not notice their own group being at all; they occupy an unmarked, neutral, apparently universal position. But victims of cultural imperialism cannot forget their group identity because the behaviour and reactions of others call them back to it. I am interested in the body and its relation to subjectivity/identity/difference/otherness, particularly whether and in what ways these perceptions are culturally influenced. Most issues of otherness focus around the body in some specific way(s), for example, 'race', gender, or sickness are often, literally inscribed upon a person's body. This chapter examines some of these ideas in relation to themes of otherness I heard whilst working on the home help evaluation. They are 'race'/ethnicity, gender, and illness.

I am also interested in questions of embodiment and how discourses of otherness become inscribed on the body. I see embodiment as referring to two

intersecting positions. Firstly, embodiment is about the experience of corporeality. Secondly, it is the learning of a set of knowledges and competencies, which can be habitually reproduced. Embodiment is therefore about how the bodily bases of people's actions and interactions are socially structured in different ways (Shilling 1997: 65). In this way, embodiment has a crucial role in the production of a certain identity, or set of multiple, intersecting identities. It is not residual to social organisation, instead, social organisation is about the reproduction of embodiment. The exchanges among the natural, the institutional and the discursive that we see in the process of embodiment occur across all social activities and operations. It is anything but a neutral constant in social life, representing instead the political principles of class (à la Bourdieu), gender and racial domination (Frank 1990: 42).

Bodies, and embodiment are important because these are the actual real life sites and experiences where 'race', illness, otherness and marginalisation collide and are perpetuated. These identities lie in the body and how we experience our bodies is dependent on factors largely outside our control. The study of racism, social inequalities, and health are all concerned implicitly with the location, movement, and care of bodies (Shilling 1993: 20). I have addressed the question of how some groups have become seen as ugly and fearful bodies in Chapter 3, where I examined the processes by which nineteenth-century scientific reason othered bodies in terms of both 'race' and illness. In Chapters 2, 3, 6 and 7 I have developed these ideas further, by discussing 'race' and disease and their contemporary links to otherness. Bodies are as much a cultural construction as a given reality. They are located and shaped through discourses, institutions and their corporeality. Therefore, when examining how the body is

experienced, interpretations and explanations must be rooted in the historical and geographical context in which the body resides. For example, the ways in which I experience my own body are largely influenced by the Enlightenment ideas of human anatomy and physiology, dating from the end of the eighteenth century (Foucault 1976). But other people do not necessarily draw upon the same frames of reference, as I show in this chapter.

In this chapter I want to build on these ideas with reference to the research I undertook in New Zealand. I examine what the discourses and narratives of the body were about, and what they might tell us. I do this by examining stories collected from the home help evaluation, but consider them within the much broader context of Maoridom and Aotearoa/New Zealand. These stories contextualise some of the many facets of difference through notions of embodiment that I saw whilst undertaking the home help evaluation. They hinge around notions of the body, difference and identity, both at the individual and group level. I am therefore able to further explore socio-cultural dimensions of health and illness, and to consider how these aspects are played out on real bodies in real life.

In Chapter 2, I examined carefully what a poststructural reading of the body might look like. Briefly put, this approach conceptualises the body and subjectivity as constantly changing, continually in flux, a product of certain kinds of knowledge which are subject to change through time and space (Featherstone et al 1991; Foucault 1980; Jackson and Penrose 1993: 14; Nast and Pile 1998; Pile and Thrift 1995: 3). Bodies therefore possess a spatiality in that they are the site where 'constellations of power-knowledge are

inscribed...through which particular subject-positions are constituted' (Gregory 1994: 584). Bodies are not only shaped by social relationships, but enter into the construction of these relationships in a way that is modified by historical, geographical, political and cultural circumstances. Perceptions of the body are mediated through language and the surrounding culture, located within competing discourses of the era. For example, what is considered ugly or beautiful or diseased varies from place to place and throughout time. Societies construct bodies in terms of shaping (or misshaping) them and deciding what is desirable or undesirable. In addition, body image is important in establishing identity (Cohen 1993: 120), and perceptions of our own bodies are also culturally controlled (Bordo 1990; Martin 1990). Thus in the South Pacific, for example, cultural shaping of the human body means that obesity is not seen as ugly or unhealthy, but as a display of wealth and beauty. By contrast, in British society, obesity is seen as an undesirable condition usually brought about by lack of self-restraint.

Pile and Thrift suggest there are five related but distinct approaches to the study of the body (1995: 3). The first approach they term logical and is that "...which sees the body as a part of a general temporal and spatial logic, an order of connection, time geography and similar attempts to map the logic of corporeality". Secondly, the body is seen as part of a prediscursive realm, through an emphasis on our experience of bodily movement, which provides us with a way of accessing the world and the object. Thirdly, drawing from psychology, the body is seen as an origin, whether as identification with the father (Freud) - or the mother (Irigaray) (see also Pile 1996). Fourthly, the body can be a site of cultural consumption, a surface on which to be written (Grosz

1991). In this approach the body is important only insofar as it is deemed to be by factors external to the body be they social systems (Turner 1992, 1995, 1996) discourse (Foucault 1976, 1977, 1981) or shared vocabularies of the body (Goffman 1963). Lastly, the body can be physically constructed in ways that were not available before. For example, the uses (and abuses) of plastic surgery enable the body to be continually re-presented (see also Cartwright 1995 for a fascinating history of the medicalised body as presented by the film industry).

8.2. DISCOURSE AND THE BODY.

The work of Arthur Frank (1990) suggests that bodies exist among discourses and institutions. He claims that discourses imply cognitive mappings of the body's possibilities and limitations, which bodies experience as already there for their understanding. However, discourses only exist as they are substantiated by on-going practice or retained by actors as 'memory traces'. By this he means that discourses exist only in the instance they are spoken, or as vague memories of that speech act. Because a discourse can only be spoken or enacted, it is nowhere but in that act or speech. On the other hand, he argues, institutions have a specificity within both space and time. It is a physical place where one can go, which may or may not be there any longer. Now, bodies do not emerge out of discourses and institutions, but out of other bodies. Corporeality, he admits, is an obstinate fact. Bodies exist in time and space as physiologies, but he reminds us, physiology is, at any given time, produced in a discourse which seeks some 'truth' of bodies. The body is therefore situated at the intersection of institutions, discourses and corporeality.

A poststructural approach views the body not solely as a given reality, but as the product of certain kinds of knowledge which are subject to change. Thus the body is conceived as a set of practices or 'body techniques' which represent and regulate bodies in time and space. Bodies are not shaped simply by social relationships, but they enter into the construction of those relationships. They are both helped and hindered by historical, cultural and social factors. From a poststructural viewpoint, biopolitics of the body are of central interest. This is where the state controls, regulates and surveys the conduct of bodies at individual and group levels in order to maintain social stability (Armstrong 1983, 1987; Foucault 1976, 1977; Lupton 1994: 21-22; Turner 1987, 1992).

Foucault focused on bodies and discourses because he was interested in how particular kinds of subjects (for example, the mad, the ill, the criminal) were produced as effects of discursive and power relations (McHoul and Grace 1993: 91). In this sense, he could be said to analyse bodies poststructurally. He considered the particular historical conditions that made various types of subject possible. Thus for Foucault, the body, and what we might know about it, was and is profoundly influenced by contemporary discourses: bodies are acted upon in discursively constituted institutional settings (Lash 1991: 259). Institutions like the penal system, medicine, education, and psychiatry, define the limits of human behaviour and record activities. Those with bodies that violate the boundaries get punished so that they become politically and economically useful. In each historical period, bodies are normalised and drilled, albeit in different ways, so that society might be reproduced. In the contemporary era, bodies have become the subjects of surveillance, so that now, bodies discipline themselves. For Foucault, therefore, the body is the ultimate site of political and

ideological control, surveillance and regulation (Lupton 1994: 23). It is the surface upon which power relations are inscribed. The body is the only irreducible in Foucault's scheme, because that is the site at which all forms of repression are ultimately registered (Harvey 1990: 45). It is also a central and active site for the resistance of, and the appropriation of, power.

Foucault's bodies are cross-cut by the power of knowledge and by the use of knowledge by power. In *Discipline and Punish*, he documents the change from inscribing literally, the punishment on the bodies of offenders in a public ritual to a new situation, where the body becomes the focal point for the exercise of disciplinary power. Power or punishment does not act directly on the body, but through the 'disciplinary gaze' which acts to produce a 'bad conscience' which becomes attached to bodies. Similarly, in *The Birth of the Clinic*, Foucault describes an 'anatomical atlas' which is the human body as constituted by the scientific medical gaze. By the late twentieth century, this biomedical conception of the body has become thoroughly normalised, and there is little recognition that there might be other ways of conceiving of the body and its illnesses. This, of course is one of the major failings of the biomedical model, and I have already discussed this at length in Chapter 1.

The disciplined body is visible in public health discourse, dealing with control, asceticism and health (Lupton 1995). It is, also, of course, already subject to the medical gaze. The body is something to be wary of - potentially dangerous or problematic, attracting disease and posing a latent threat to the rest of society. In the case of infectious diseases, measures are taken to confine bodies - and control where they go. This type of control in the name of public

health has often been coercive and discriminatory, for example, in the past, 'contaminating Others' have included Jews, foreigners, and the 'working classes'. Today, HIV/AIDS is still commonly seen as a disease of black Africans and gay men, and public health measures are specifically directed at these sub-sections of the population.

8.3. DISCOURSES AND NARRATIVES OF MAORI BODIES.

In the contemporary setting of colonisation, Waller (1998) has written about Maori experiences of the body from the viewpoint of the film, *Once were warriors*. He argues that Maori identity is depicted as a collection of urban survival sites once occupied by members of a single family. Waller analyses bodies and places in the film images to question what 'traditional' Maori identity might be in a postmodern urban world of juxtaposed cultural styles and places. He concludes that in literal ways, the spaces of Aotearoa/New Zealand constitute and in turn are constituted by the Maori body, that is, the bodies in the film are, to follow Grosz's formulation, the '...sites of social, political, cultural and geographical inscriptions' (1994: 23).

Waller's work concentrates on young Maori in an urban setting. In contrast, this thesis focuses on predominantly old people (both Maori and Pakeha) in a rural context. Even though the focus is different, I think Waller misses two important points about Maori experiences of bodies. First, that they are intricately bound up with land (alienation) and the environment, a point I elaborate in the next section. Second, the question of body image. Western and European body ideals hinge on (overly) slim bodies (Benson 1997; Bordo 1990,

1993; Martin 1990; Turner 1982, 1982a; 1992), In contrast, Maori bodies that are thin are not necessarily looked upon favourably. Body image is traditionally regarded differently by Maori. Beauty and wealth are manifested in well-rounded forms, and obesity does not provoke the same sense of disapproval encountered in society generally. Durie has argued this is an important reason why anorexia nervosa remains relatively infrequent among Maori girls, and why health workers report difficulties in trying to persuade Maori patients to lose weight (1994: 73).

These kinds of perceived beauty are not always well received by Pakeha. Amy, for example, is an elderly Pakeha lady, of 79. She originally came from Scotland and has been in New Zealand for many years. She retired to the Hokianga with her husband 12 years ago. She told me that by Hokianga standards, she is a newcomer and on occasion, still considered an outsider. Her life experiences and late arrival in the Hokianga are reflected in this passage:

“Fat is wealth with the [Pacific] Island people, as you know. But they’re gradually learning. And the Maori people for that matter. But it’s taken them all those years to gradually learn that you don’t have to be fat. And to eat sensibly. But you still get them. Dear oh dear. Its a sign of wealth. You have money. The fatter your wife is, the more the husband’s thought of. If he’s got plenty of money. The King of Tonga - Oh! Dear! He was just hanging in fat! Literally hanging in fat! He could hardly move about. And they got him exercising and on a diet. And he’s now speaking out for his people and encouraging them - telling them that it’s not healthy to carry all that weight. And he’s got them all on to it as far as he can. Showing them that this is the way to go. Which was good. But er - and here. A lot of them have managed to eat sensibly and that. But then again - others you wonder how on earth - or how old they are. Until suddenly you discover some of them aren’t even out of school. And they’re carrying *so much weight*. It’s terrible. It really is. Honestly. The Maori people - it’s not culture but form. That’s an understood thing. But they have extremely

big hips and they would be better if they ate well. Ate properly. Not so much fatty food. Great ones for fat. Fat pork”.

This is an interesting passage, in that it brings together many of the previous arguments outlined in Chapters 2, 3 and this chapter. Clearly, there are several discourses circulating through this passage, but here, I concentrate only on two; discourses of ‘race’ and of public health in relation to the body. Amy is clearly influenced by facets of the racist discourse outlined in Chapter 3. She lumps together people of colour - in this case Maori people and Pacific Islanders as the same. She sees them as slow to learn ‘wayward children’ that need to be civilised into ‘normal’ modes of thinking, in this case, thin is good, fat is bad. Yet although there are similarities between these cultures and peoples, I would hesitate to consider them under the same umbrella. In my experience, Pacific Island and Maori have as many differences as similarities. (The University and Regional Health Ethics committees also showed a degree of sensitivity to difference, by insisting that the consent forms for this project were available in English, Maori, Samoan, Tongan, Cook Island, and Niuean languages, see Appendix 3). In addition, I would want to demonstrate an awareness and a respect for peoples different origins and histories¹. Racist discourse also permeates Amy’s comments that Maori and Pacific islanders are slow to learn, that they are “...*gradually* learning...[b]ut it’s taken them all those years to *gradually* learn that you don’t have to be fat...” (my emphasis). That Amy considers these people slow to learn invokes the higher mental faculties argument outlined on page 79 (Belich 1986: 326; Pawson 1992: 26). She sees people of colour as slow to pick things up, and therefore simply not as intelligent

¹Being married to a Welsh man I have had little choice.

as Pakeha or other white people. Not only are they mentally slow, they are also anatomically distinct. Amy stereotypes Maori as having big hips - "not culture, but form". Again, this invokes notions of racist discourse, where in the past, Victorian classificatory systems for measuring human anatomy were popular. It also suggests to me, shades of the Hottentot Venus, implying certain judgements on Maori sexuality too.

Another discourse filtering through the above passage is that of medicine and public health, where the disciplined body is evident. In the late twentieth century, these discourses deal predominantly with notions of control and asceticism, largely through diet and exercise. Public health discourse is focused in controlling bodies, through people taking responsibility for maintaining their own health. Bordo (1990) has argued that this preoccupation with fat, diet and exercise functions as one of the most powerful 'normalising' strategies of our century. It encourages, if not ensures the production of self-monitoring and self-disciplining 'docile bodies', sensitive to any departure from social norms and conditioned to self-improvement and transformation in the service of those norms. Culture, she argues, is being converted into automatic, habitual bodily activity. According to Lupton (1994: 31), the dialectic of public health is that of the freedom of individuals to behave as they wish, pitted against the rights of society to control individuals' bodies in the name of health. This dialectic is operating in Tonga. The King of Tonga is exercising and on a diet. It is significant that the Head of State is telling Tongans what is good for them, because as I identified in Chapter 2, one level of analysing the body is through the social body (Lupton 1994: 22; Scheper-Hughes and Lock 1987: 8). Influenced by discourses of public health and medicine, the King is using his

position as Head of State to use his body a representation for the rest of the state, a symbolic representation of nature, society and culture. Moreover, he is telling people that it is not good to carry a lot of weight. Turner (1992) has developed the notion of a somatic society in which the body is a metaphor for social organisation and social anxieties: the principal field of cultural and political activities. The regulation, surveillance and monitoring of bodies is central to the somatic society. It would appear that through the infiltration of western discourse, Tonga is well on the way to becoming another somatic society.

Whilst interviewing people for the home help evaluation, I noticed that the topic of people's bodies often arose, even though there were no explicit questions about this during the interview. Interestingly, Maori participants had far more to say about this issue than Pakeha. I believe this is because Maori conceptions and experiences of the body are quite different to Pakeha ones, and because Pakeha discourses tend to be hegemonic, their conceptions of the body are perceived as 'natural' and 'normal' and therefore go unproblematised in everyday life. The importance of the body, and of body parts is reflected in *te Reo*, the Maori language. For example, *hapu* means both pregnant and a section of a large tribe; to give birth is *whanau*, it is also the word for the extended family; and *whenua* means placenta, land, country and ground. As Perc points out, from a Maori perspective, "the placenta embraces and cherishes the child in the womb. The land offers one the same feeling of warmth, security, nourishment and sustenance, a feeling of belonging" (1991: 22). *Rae* is either the forehead or a land promontory; *iwi* refers to a bone (*ko-iwi*), or to a nation of people; *wairua* refers to spirituality and can also be used to refer to an insect. *Kapo* means blind and a species of eel; *whakapo* is to darken as in approaching

night and to grieve; *waimate* is a hereditary disease but also polluted water; *kauae* can be the jawbone or a major supporting beam in a building; *tauhuhu* is both the vertebral column and the ridge pole of a meeting house (Durie 1994: 72). These examples show how Maori conceptions of the body are reflected in and through language, embedded and embodied in everyday life, from birth to death.

For Maori, certain parts of the body are *tapu*². Various parts of the body, for example, the head, genitalia and heart are devised as having special significance, although not necessarily at a conscious level (Durie 1994: 68). Maori may resist surgery because they regard it as mutilation of the body. Cuts to the body are considered generally shameful, unless they occur in battle, tattooing, or mourning. Maori also tend to resist post mortems because of the disfigurement to the body. Body disfigurement or dismemberment is a cause of distress to Maori, not for cosmetic reasons, but because of the belief that in the afterlife, they will take the form that they had had in the early life. The loss of body parts, particularly limbs, is therefore of great significance. To incinerate limbs or body parts as is usual in western hospitals is to transgress Maori custom. Relatives will wait about in hospitals to receive amputated limbs and other body parts, to take 'home' to the cemetery for appropriate burial. Sarah told me her story one day. I recorded it in my diary when I returned home:

²There are many meanings and conditions associated with *tapu*, which means sacred, or set apart. In the context of the body, it includes all kinds of restrictions and prohibitions, such as people handling the dead, and women during menstruation (Barlow 1991: 128-129).

“Sarah mentioned she’d had her ovary out last year. She explained how all body parts whether arms, legs, ovaries or afterbirths are given back to the person from which they came. Then they are buried. Sarah buried her ovary in her parents grave.” (Diary 2, 29.5.96.)

I was touched that Sarah had shared this knowledge and these experiences with me, because clearly, they are very intimate and personal things. She also told me how difficult it can be in some New Zealand hospitals to actually get back one’s body parts. She voiced some scepticism about the process, and said that one never really knew if they were getting their own body parts back or not. For Maori, any body intervention, however seemingly mild, requires a measure of caution and circumspection.

The following comments not only support this assertion, but add to the ideas in the previous chapter about privacy, dignity and allowing *whanau* to be home helpers. Obviously, it is vital for personal care givers to be cognisant of cultural preferences, which is partly why family are sometimes permitted to undertake certain duties. This way a person’s dignity is better maintained. For Maori, the head is the most sacred part of the body. This means that for some carers (particularly if they are Pakeha, or unrelated to a Maori client), washing hair might be an awkward task. Carers need to know that hair should be washed before the client actually gets in the bath, rather than once they are in it. Hair must not become contaminated by the water that your body sits in. Nancy is a Pakeha home helper looking after an elderly Maori lady. I asked her if there were any cultural taboos that she had come across whilst looking after Winnie. She told me that:

“Some things on tables and touching their heads - its really - you’ve got to be really careful. You know, no one told me those sorts of things - you sort of pick it up along the way. It was hard. Really hard. Heads aren’t touched - well, its really hard coz I have to wash her hair and comb her hair everyday. I try and do it without any force - like really light touching. I mean - you can’t not touch their head when you’re washing their hair. She absolutely *hates* it. But she’s senile to the point where she - I mean she can’t say - she used to fight about it. She’d say no, she didn’t want her hair washed. For days on end. I’d just finally say, “Look, you know, this is happening, close your eyes. Forget about it and I’ll do your hair”. It was hard coz she’d fight me to the point where she would rather have greasy hair and an itchy head. Than have her hair washed. And I knew it was coz she didn’t want me touching her head.”

This kind of knowledge seemed common amongst the home helpers in the Hokianga. Most knew about the sanctity of heads and the delicacies involved in attending to bodily hygiene. It was, if you like, common knowledge. Sarah told me that:

“...leaving [hair] brushes - round food tables or anywhere near food is like a real sensitive subject for them. Combing their hair or anything in the kitchen areas - putting your feet up on their chairs and things like that - sitting on the food table - even the basins and that you know? Like the basin that they use for making maybe their bread or something like that and even if you just wash your hands in it - that dish’ll go out the door. And when they take their hair off their brush, they wouldn’t throw it in the fire or a rubbish bag or something like that. They would probably roll it up into a ball, and maybe one day when they’re out in the - you know - you might get all these little balls - round the window sills and that?³ And then one day when they’re going outside and maybe dig their garden, they’ll dig a hole a little bit deeper, go pick up all these little balls and they would bury them. And they don’t like anyone touching their hairbrush or anything, because of their hair.

³And of course, the home helper must know they are not allowed to throw these hair balls away.

Nails are also sacred too. Neither should be cut after dark. All should be put back into the earth. Hair - if a person dies, to show that you were very respectful and loved them dearly, you'd put a lock of your hair on them. A child's first haircut is no minor affair. The person who cuts the child's hair for the first time is carefully chosen. In a way, it's a kind of godparent type relationship. They will look out for that child - even as an adult. If I died, then a lock of grandchildren's hair was put with me, I would be looking after that *mokopuna* even in death, because hair never dies."

These comments interested me because they were direct contradictions to what I had been told by the Maori professor at the University of Auckland⁴. There, I had been told that to search for differing conceptions of health and the body was a futile quest; that Maori simply did not think in those terms. Well, I was finding quite the opposite. The Maori participants *definitely* thought about their bodies in different ways to the Pakeha participants, myself, of course, included. One difference was in the way Maori participants connected their bodies to the land. People I spoke with did this in two ways. First, there was the way described above, where the earth plays an important and literal part in the everyday lives of many Maori. Things are buried in it. Cultural traditions and preferences are maintained. The concept of *turangawaewae* cannot be adequately translated into English, but is basically a place to stand, as of right (Pere 1991: 50). It is the place to where a person belongs, and from this place, a person can move into any given context, knowing that he or she is sure of their identity. The importance of history, genealogy, legends, proverbs, songs, obligations and responsibilities means that people know where they came from, giving the person greater control over their life. Second, as already discussed in Chapter 3, and similar to other marginalised, indigenous groups, access to

⁴I have already described this encounter in Chapter 4, pp. 150.

traditional lands means access to other factors vital for health, for example, cultural institutions, autonomy, and economic chances (Durie 1986; Pomare and de Boer 1988). The population collapse following colonisation was especially severe in New Zealand, because of the amount of land dispossession (Pomare et al 1995). Pool (1991) has shown that Maori child to women ratios were lowest in the areas where land seizures were occupying most rapidly. Land alienation not only made people poor, but also made them more susceptible to diseases which flourish under conditions of poverty, overcrowding and malnutrition. Social networks which provided practical and emotional support in times of need were therefore destroyed or at least, disrupted. This legacy of colonial history continues to affect Maori today. It is reflected in low incomes and other markers of socio-economic status. This status is in turn, a significant factor influencing health.

8.4. DISCOURSES AND NARRATIVES OF GENDERED BODIES.

Many feminists who write about the body have been profoundly influenced by the work of Foucault and other poststructuralists. For them, the (female) body might be conceived as an inscriptive surface (Grosz 1994); the pivot of the 'reproductive arena' (which is *much* more than simply having babies) (Connell 1997); as constituted from complex categories constructed in contested sexual scientific discourse (Haraway 1991); or as a performance Butler (1990). Foucault has argued that the body is a surface on which the operations of power, knowledge and resistance are worked out. Through social norms, self surveillance and disciplinary practices, the body's materiality, and its desires and pleasures are produced and restricted to a narrow range of acceptable

attitudes. For Grosz (1994) the body is an inscriptive surface because of the ways in which we present our bodies. Its size, its shape, the gestures we use, the space it takes up, the masculine and feminine norms that men spread out and women don't, all go to make up the nature of the body, what is acceptable and what is not. For Grosz, it is the differences in physicality that construct and reflect gender norms create ways of being in space. The body is an object over which we labour - dieting, exercising, plucking and decorating to conform to an idealised view of an appropriate femininity or masculinity. Grosz emphasises the need to understand the body not as a neutral surface or as a naturally differentiated, already sexed form, but as socially-located morphologies. She argues that biological differences themselves are constructed and translated by social practices, and that sex and gender are inextricably interlinked rather than the latter being a cultural imposition on the natural/biological former.

Connell argues that gender is one significant way in which social practice is ordered (1997: 44). Gender relations, that is the relations among people and groups organised through the 'reproductive arena' form one of the major structures of all documented societies. Gender is a social practice that constantly refers to what bodies do, it is not social practices reduced to the body. Social practice is creative and inventive, it responds to particular situations and is generated within definite structures of social relations. In gender processes, the everyday conduct of life is organised in relation to a reproductive arena defined by the bodily structures and processes of human reproduction. This arena includes sexual arousal and intercourse, childbirth and infant care, bodily sex difference and similarity [and, I would add, menopause and post-menopause]. Connell refers to this as a 'reproductive arena' not a biological

base, in order to emphasise that she is talking about a historical process involving the body, not a fixed set of biological determinants. The view that notions of the body change with historical and geographical circumstances clearly places her within the poststructural camp.

For Haraway there is nothing natural about being “female”, itself a highly complex category constructed in contested sexual scientific discourse and other social practices (1991). For Butler, sexed bodies are constructed as such retrospectively, from the standpoint of already dichotomised gender - that is, intersexed bodies are constructed, linguistically and medically as male and female. Butler analyses gender as performance, arguing that the rules and regulations of social life require the performance of a heterosexual gender identity. She suggests that gender identity is neither neutral or fixed, but rather that the lived body in space is the outcome of culturally sanctioned fantasies. The appearance of a coherent gendered identity must be constantly created through the performative repetition of bodily acts and gestures. Gender is therefore a fiction or a fabrication that requires constant regulation.

For feminists, issues of embodiment and the body have always been key issues and their work has been instrumental in generating interest in the nature of the body (McDowell and Sharp 1997: 201). At the same time, one of the key aims of feminist politics has been to challenge the medicalisation of ‘female complaints’ from menstruation and childbirth to the menopause. Young has argued that women’s oppression is structured by the interactive dynamics of desire, the pulses of attraction and aversion, and people’s experiences of bodies and embodiment (1997: 220). Women’s bodies are perceived as changeable,

fluid, and powerful, their life giving properties constructed as threatening by men. They are seen as fleshy temptation or as pure embodied delight to worship (McDowell and Sharp (1997: 201). McDowell and Sharp (1997: 201) argue that of all the dualisms that have structured women's inferiority, it is the mind/body distinction that has posed the greatest challenge. Through the development of Enlightenment thought, the mind has become associated with masculinity, the body with femininity and this dichotomy has been reproduced in the social and political spheres. Feminists began to consider this mind/body duality explicitly in the 1970s (Cranny-Francis 1995; McDowell and Sharp 1997). For them, the links between women or femininity and the body were crucial. Physical embodiment was conceived of in two broad, but related ways: sex was defined as the biological differences between men and women, and gender was theorised as the sets of cultural attributes mapped onto male and female forms; socially constructed and historically and spatially specific (McDowell and Sharp 1997: 201). More recently, feminist scholarship has dissolved the sex-gender distinction, as new ways of theorising the body have developed. New (1997) maintains that sexual difference is real, though not merely dichotomous. She argues that it is no accident that human beings have been able to dichotomise it more or less successfully: sexual differences do have a bi-polar distribution, explicable by evolutionary accounts of sexuality. There are real male and female capacities and liabilities, although whether and how these are established in particular cases depends on the entire causal context.

For women embodiment is contradictory. Young (1997) suggests "while a certain cultural space is reserved for revering feminine beauty and desirability, in part, that very cameo idea renders most women drab, ugly, loathsome or

fearful bodies. Tseelon has argued that five paradoxes construct feminine embodiment. These are (i) the modesty paradox, that is, woman is constructed as seduction to be punished for it; (ii) the duplicity paradox, where the woman is constructed as artifice, and marginalised for lacking essence and authenticity; (iii) the visibility paradox, where the woman is constructed as a spectacle while being culturally invisible; (iv) the beauty paradox, where the woman embodies ugliness while signifying beauty; and (v) the death paradox, the woman signifies death as well as the defence against it. These five paradoxes are helpful in understanding the representations of woman and the social practices that result in women's exclusion from positions of power in the public arena.

Whilst collecting stories about home help in the Hokianga, it became apparent that discourses and practices in daily life, especially Maori everyday life, were clearly gendered and embodied. The experience of corporality differs markedly between Maori men and women, and the learning of a set of knowledges relating to this are habitually reproduced. I would not want to claim that Maori society *necessarily* has more clearly defined gender roles than Pakeha society, but because I was immersed in a predominantly Maori area, I simply heard more about Maori everyday life than Pakeha ones. Most of the Maori men and women I spoke with accepted and embodied their gender roles without question. Women saw certain household tasks, such as child-rearing and domestic chores, as theirs. Men had other, well-defined roles, such as fishing and eeling, car maintenance, doing the heavier garden work, and certain *marae* obligations, depending on their age and status. There was little criticism of the division of labour within Maori life. For example, Wiri told me of his home help:

“A woman knows a house eh? Women make better home helps than men. Oh, definitely. Men’s outside eh? [although he gets his female home help to mow the lawns!] All women are good you know. Its all bad husbands, eh, you know? You know every woman’s good you know, she’s got something. Oh, women are pretty good, you know. As long as its not a young girl. You know, young kids and that. A married woman is good [as a home helper].”

And to recall some of the comments made by Kare in the last chapter:

“Like er, with me, with my clothes to be washed...It’s not a husband’s place to do washing - well - in a Maori way anyway. My undies and my tights I don’t give my husband to go and do those. If I’m in the shower, I’ll do it myself. He doesn’t know I’ve got it in there...and my rags, you know [she suffers from stress incontinence]...Otherwise Dad’d have to do it. I don’t want Dad to do it. I don’t want to see what’s - you know. Although he’s my husband, but he’s never seen that sort of thing...”

This gendered division of household labour is embodied in the ways I outlined earlier in this chapter. The experience of corporeality varies between men and women, and this is largely because of the habitual reproduction of sets of learning and competencies which are thoroughly gendered. Thus child care, or housework, for example, are seen as ‘naturally’ a woman’s job.

It is important to recognise diversity between Maori tribes, and not to oversimplify that diversity. However, for many, if not most tribes, one of the prime sites for the habitual reproduction of gender roles, and with an explicit focus on men’s and women’s bodies is on the *marae*. The *marae* is a symbol of traditional identity which in contemporary times can be thought of loosely as community facilities, encompassing buildings and land (Barlow 1991). The *marae* consists of a carved meeting house, a dining hall, and cooking area, as well as what was the original meaning of *marae*, the sacred space in front of the

meeting house. The *marae* complex has many male and female associations. Whilst it is being built, women and food are strictly forbidden to enter, as this is the time it is at its most sacred. It is often named after a male ancestor, and its design and structure represents the ancestor's body in quite literal ways. In many *marae*, for example, there is a carved head (*koruru*) between the bargeboards of the porch. This is said to represent the ancestors head. The bargeboards themselves are seen as the ancestor's arms held out in welcome, and carvings at the end represent his fingers (*raparapa*). The ridgepole of the house is the ancestral spine, the rafters the ancestor's ribs, and descent lines, and the interior is his belly.

Within the meeting house, the right side is *noa* (common, in the sense it is not sacred or governed by *tapu*), the left side is *tapu*. The right side of the meeting house is associated with females, life and the rising sun, whereas the left side is associated with men, death and the setting sun. Males, high descent, the elderly, the dead, and the history of the tribe all possess *tapu* qualities. The most sacred rituals relate to this complex in that they are practised by elderly male aristocrats, and they are invoked in the presence of death. On the other hand, women, the low born, cooked food, water and the young all have *noa* qualities. They are therefore prohibited from carrying out sacred rituals. A strong division holds between the *noa* cooking-area, run mainly by the middle-aged and young, and the *tapu* ceremonial area. Women have supportive role in this area only, and in most tribes are excluded from the central activity of making speeches⁵.

⁵In the past, if there was an offensive speaker on the *marae*, the traditional way

Barlow (1991) has argued that in Maori culture, a woman's primary role is to nurse a child until it grows into maturity and independence. He describes women as the 'house of mankind' because all humans are conceived and develop in the womb. A woman suffers much of the pain and sorrow associated with bearing and raising children, and she is responsible for the child's physical growth. On the other hand, the husband or father is responsible for the child's spiritual and moral upbringing. Spiritual and moral upbringing is privileged over physical upbringing, it is therefore a man's job (Barlow 1991: 148). This is unsurprising, given the role and position (both literally and metaphorically) of men on the *marae*, and in Maori society generally. Their *tapu* qualities means it is logical for them to take charge of the moral and spiritual development of the child. Women, as *noa* are in charge of the *noa* qualities and physical development of the child - feeding it, clothing it and the like.

Pregnancy, childbirth and menstruation.

The importance of Maori *whakapapa* genealogy means that pregnancy is an important time. When a child is conceived and develops, the condition is known as *wheiao*. The child is imbued with power from the gods in the form of a *mauri* (life-force), which gives the child the power of life and his or her unique characteristics. I have already introduced the concept of *mauri* in Chapter 3 as the sixth tentacle of *te Wheke*. Although the concept is hard to define in English,

to silence him was for the old women to bend over and flip up their skirts at him. This graphically expressed the opinion that the speaker was *noa*, like a woman, and should no longer speak on the *marae*. I have not heard of this happening in the Hokianga, although that doesn't mean it never has!

broadly speaking, it refers to a person's life principle and psyche. *Mauri* must be appreciated and respected, because it helps people relate and care for everyone and everything across the universe (Pere 1991: 12). Strictly speaking, the *wheiao* is the stage just prior to birth, when the child's head is engaged and birth is imminent. The journey from the womb to the outside world is also a state of *wheiao*.

After the birth of a child, it is customary to bury the placenta and umbilical cord in a sacred or special place. Burying the placenta (known as *whenua* which also means land) ensures continuity with the past, and the place of burial may well be where the person is eventually laid to rest. This is a close and highly significant link Maori have with their ancestral land. The umbilical cord is also put in a container or bottle, and taken to the family cemetery. An entry in my diary tells of Maori practices in the Hokianga:

“Afterbirths - Sarah is a member of the Catholic church. Their church is on an acre. One area is dedicated for their afterbirths. She drew a picture in the air. Every time an afterbirth is buried, a bush is planted over it. That way others can know another afterbirth has been buried. The bush is sacred. Families tend to have ‘patches’. For instance, Sarah's daughters would bury their kid's afterbirths near the bushes that were planted for Sarah and themselves.” (Diary 2, 29.5.96.)

Although I had not set out to discuss the matters of pregnancy, childbirth, and menstruation during the home help interviews, these subjects invariably came up, mostly because of my own pregnancy. As I have already said, this was a great ice-breaker, and it seemed that women would talk to me about their own experiences, precisely because I was pregnant. I was given much advice during the interviews, some of which I have included in this section. One

interesting conversation I had was with Sarah, and a young home helper, whose name was Rosie. She was brought up by her grandparents in 'the traditional' way. Between them, Rosie and Sarah told me what I must (and must not) do, for a successful pregnancy:

Rosie: "I was taught like that - not to cut your hair when you're pregnant."

Helen: "So to be a good Maori I mustn't get my hair cut for the next six months?"

Rosie: "Oh no! No! *No!* Don't cut your hair! They say that a lady who's pregnant that cuts her hair it taking out some kind of thing - um - the strength away from the child".

Sarah: "And if you've got a toothache, when you're carrying - coz nine out of ten - everybody - well 88% gets a tooth out while they're carrying - they get toothache while they're carrying. Not all but the majority. So if you get your tooth pulled out - make sure you take it home with you. So if it ever happens to you, take your tooth home with you".

Helen: "And bury it in the garden?"

Sarah: "Yes. They reckon that's your child's wisdom. That's what makes your teeth. That's where the child gets it's wisdom from. Not wisdom teeth, just wisdom! They reckon quite a few pregnant mothers - it didn't happen to me. I didn't have anything like that. They reckon a lot of them they can count in their mouths how many babies they've had just through the amount of teeth they've got missing. So that's what you do if you do get a toothache."⁶

⁶I was lucky. I didn't lose any of my teeth during my pregnancy. But I have to confess to getting my hair cut once the fieldwork had finished.

Rosie also brought up the topic of menstruation in relation to home help, because there were certain things she could not do as a home helper when she had her period. She told me that:

“A lot aren’t allowed out of the house- once I got to that age group, “I’ve got my period, O, gosh, I’ll stop in the house.” I do all the inside work, but the gardening - even just to pick up the rubbish from the garden - is a no no. You just stay inside until you know - just do the cooking, cleaning, or whatever...we weren’t allowed to hop on horses or go swimming. We had to stay away from anything to do with outside activities. And the old people know, you know? There is *no* pulling the wool over their eyes⁷. In our case, when it came to sanitary pads there were three of us - three girls - we always - wouldn’t use the same rubbish bag as - you know - the normal rubbish and everything? We’d always keep our own separate one - and she always used to dispose of it. I don’t know how. All Maori women. All Maori women, I’m telling you! That’s in my upbringing. Brought up that way. To be private to yourself. You’re brought up that way you know, and once you have your period that’s it - you’ve got to do those things yourself privately. We were brought up that way and it sticks to you.”

Sarah expanded this further:

“...you weren’t allowed into the garden if you had your period. That’s where you’d normally go to plant your vegetables or dig your veges out. It’s disrespectful to the earth. Because your period is connected to that - *whenua* - oh - to the earth. Your period is connected to the *whenua*. So you shouldn’t disturb the *whenua* when you are like that. Disturb the earth...A few have actually lost - our old ways. You’ll find that a lot of people who have been brought up by the old people have still got it. You can see that they feel guilty - they do it but quite - but they still know they shouldn’t be doing it.

If you had your period - especially back in the hey days - they used to have - you had a special towel for that? And they used to wash them and all that, you know? They *never* used to dispose of them. And when sanitary towels and that came in, they used to actually have a

⁷Its not just the old people who know certain things. Sarah knew I was pregnant long before I found out myself.

special - burial place - to bury them. But the young girls used to take theirs away and they used to want them burnt. But of course *again*, the girls used to get a bit lazy when it came to things like that you know? But I mean that was our own stupidity. Actually wasn't our teaching.

We had a special place that we called the rubbish tip. And we would dig a big hole - a bit like an outside toilet - we had an outside toilet as well . And we just turfed them all in there. Just throw the whole lot in there and then they could - um - well, like I say - things have changed. Now they just flush things down the toilet. Things have changed culture wise. We blame ourselves for not carrying on our own culture too.

With home help [one would need to be aware of these things] because you could go in there and you could do something wrong, eh? Go in there with your period and throw your sanitary pad in their rubbish bag. If you leave your sanitary towel in their rubbish - an elderly Maori lady - a man is worse. An elderly man is worse. He would probably take it out of that rubbish bag and do what you - probably won't let you back in his house.

Taboos surrounding menstruation, exist in all cultures, taking different forms and appearances. Some cultures literally separate women from the community during menstruation to avoid contamination or contagion, reinforcing stereotypes of women as dirty, dangerous, and unstable. In 'traditional' Maori culture, according to Rosie and Sarah, menstruating women are confined to the house and strictly forbidden to do any kind of outside activity, be it gardening or sport, for example. If they do not abide by these rules, they are breaking *tapu*. Their comments are interesting because they run counter to one western discourse on menstruation, which besieges us with adverts for sanitary products, constantly telling us we can do *anything* when menstruating, including swimming, skating and riding horses. Even so, this discourse is not necessarily hegemonic. I believe that menstruation is still taboo in our own culture. It is an embarrassing subject that 'nice people' do not talk about, and certainly not in public. This kind of discourse is pervasive in many ways: from

the discreet packaging of sanitary products, to placing it in a brown paper bag at the point of purchase. Competing discourses exist in Maori culture too.

For example, Rosie was brought up by her grandparents, whereas Penny was not. Penny is Maori, and about the same age as Rosie. She worked for an elderly Maori lady who told her:

“If I had my period, “Don’t go into the garden”. That was a no no to her. She was a Maori - she told me that straight away...because of your monthly. And that to her would be *tapu*. But she - it was good that she actually told me when I started working. Oh well, I’d just go out into the garden without her knowing! As long as she didn’t know, it wouldn’t hurt”.

Clearly, menstruation is a biological act charged with cultural implications. In turn, this helps produce the body, and women, as cultural entities. In this way, the body can be seen as a ‘text’ of culture, a symbolic form upon which the norms and practices of society are inscribed (Bordo 1989). Whether Maori or Pakeha, menstruation is loaded with the ambivalence of being a woman in western society today and one mechanism by which women become inserted into - and insert themselves - into dominant patterns of sexuality (Lee 1998). It is negative and shameful to talk of menstruation in contemporary western culture; to talk about it is to articulate its secretive, emotionally laden and shame filled aspects. This is true for both Maori and Pakeha cultures, although judging from what I was told in the home help interviews, I suspect that this might be more the case for Maori than Pakeha. Women’s bodies are thus produced discursively within male-dominated societies (Foucault 1981). Whilst menstruating women may no longer be viewed as automatic invalids in contemporary western society, menstrual rules and taboos still mark out woman

as the other, as different. The symbolic and cultural rules about dirt and pollution, in the work of Mary Douglas (1966) have been applied to menstrual discharge, as it is commonly regarded as 'matter out of place' (Lupton 1994). Menstrual blood breaches the boundaries of a body that normally contains blood unless there is injury (Buckley and Gottlieb 1988). Women's everyday experiences are concretely lived in ways that internalise and maintain such discourses, and actively resist them through appropriation and/or the integration of more positive discourses of the body. These discourses of menstruation as positive include those of fecundity, lack of pregnancy, sexual maturity, bodily order, good health, and a symbol of bodily renewal (Buckley and Gottlieb 1988; Lupton 1994).

Because cultural reproduction depends on human reproduction, questions of womanhood, such as menstruation, childbearing and child rearing are invariably significant in the life of a culture. Significant changes in personal habits, childbearing and child-rearing patterns often signal broad cultural changes (Treichler 1990 113). In the last two decades or so, the role of Maori women has changed considerably because of wider social forces. Changing family structures, the possibility of wage earning and the creation of powerful groups such as the Maori Welfare Women's League have all contributed to women's changing roles (Salmond 1975). Thus there are some women who do not subscribe to the traditional Maori ideal woman through either choice, or necessity. And some women have become powerful actors in the public arena. I have had first hand experience of this, as I recounted at the very start of this thesis: the Maori delegate who took me to task so publicly at the Third Asia and

Pacific Conference on the Social Sciences and Medicine was a powerful actor indeed.

8.5. DISCOURSES AND NARRATIVES OF ILLNESS, DISABILITY, DEATH AND THE BODY.

Illness and disability produce confusion, shock and despair. The ill want to be cared for in their physical needs, but they also need to be recognised in their condition, or, for their condition to be recognised as fully human. But narratives of illness can help render coherent the contingency and lack involved in illness, and I subscribe to this point of view (see also Frank 1990; Kleinman 1980, 1988; Radley 1993a: 121). This section therefore reflects on narratives of illness and the experiences of changed bodies that I collected during my fieldwork.

Kleinman argues that when functioning satisfactorily, we take our bodies for granted in everyday life. Illness, however, forces us to consider the precarious nature of our corporeality; it disrupts and menaces the integrity of our bodies (1988). Chronic illness is a betrayal of that integrity, and life for chronically ill people becomes a working out of the sentiments that proceed from this corporeal betrayal. For example, I remember the interview with Ivy as hard work. She was an in-patient at Rawene Hospital, having had a dense stroke. She was confined to a wheelchair, and had great difficulty in talking clearly. Her affected speech also meant it was very difficult to transcribe my conversation with her. Ivy told me, with tears streaming down her cheeks:

“Get the painful parts cut out. And leave the good parts there.
It’s so bloody painful. I’m sick and tired of this life nurse, honest I am.

Sometimes I feel like telling the doctor to inject me. To put me down eh? Yes, its that bad. I get to that stage at times - its so painful. *Wherever.*"

Ivy was truly at the end of her tether. She did not want to have to face the rest of her life in pain, and actually died as an in-patient at Rawene, three weeks after the interview had taken place. I was relieved for Ivy that she would not be in any more pain. My diary entry for the day following her death reads thus:

"I ran into Sarah this morning. I was having a cup of coffee with her when Gwen [Principal Nurse of Rawene Hospital] came in. We had already found out that Ivy had died last night. Gwen asked Sarah if, "She could sort things out." What she meant was could Sarah lift the *tapu* on the *Awhina* Room. [This is a room used as a kind of chapel of rest for a dead body to lie in and for relatives to visit]. Sarah took in Ivy's wheelchair (Ivy and her other stuff was already in there) and closed the door. A few minutes later, out she came. Anne Morgan [Principal Nurse, Community] says that she (Sarah) would say certain prayers to lift the *tapu*. Martha's body would have laid there after she died, before going to the undertakers. From the undertakers, she would go to the *marae*, pronto.

I asked Gwen if one could go into the room before the *tapu* was lifted, and Gwen replied that the room could not be used. But one could go in - to see the body etc. She mentioned that last time, the room got used before the *tapu* was lifted, and that Sarah just about had "an F, I, T!" Usually Gwen tries to get the *tapu* lifted as soon as the body leaves - usually there is a minister there. But Ivy died at half past eight the previous evening, so they had to wait until this morning in order to carry out the ceremony. Also, there was a Q[uality] A[ssurance] meeting at eight thirty that morning, so Anne and Gwen wanted it done fairly quickly, so that the meeting could go ahead.

Afterwards, I talked to Sarah. She was saying that anyone could say the prayers and lift the *tapu* after a death, "even a Pakeha or a German!" She went on to say she'd *know* if those prayers weren't said. A few of them at the hospital can tell. It would be an insult to the dead not to say them. Also, its to protect those left alive. Otherwise the person who has died can take others with them, for up to nine days after the death. (Diary 2, 21.6.98.)

Like our understandings and experiences of gender relations, how we understand and experience illness and death is also culturally biased. Biomedical approaches and explanations are but one way of seeing and experiencing disease, illness and the body. Maori approaches to these issues show marked variations from solely biomedical explanations, although biomedical explanations are important for Maori as well (see Chapter 3). Like 'the body', health, disease and illness are not simply real, but the products of social reasoning and social practices. There is not one truth about the body and disease; these categories are contingent on their social cultural and historical context. In other words they are socially constructed (Nettleton 1995: 17). Studying health and illness involves studying people's interpretations of their bodily experiences, and concerns social aspects of the regulation of bodies. As Nettleton reminds us, the object of medicine and the object of sociology (and by extension human/medical geography) is the body. But this is not the passive anatomical frame that was the focus of biomedicine, but the body that is capable of social action, interaction and its interpretation (1995: 11).

Dorn (1998) has criticised various poststructuralist feminist authors, arguing that their focus on nomadic thought and hybrid embodiment (for example, the androgen, the freak, the cyborg). He argues this has produced a dream of multiple, fractured identities, at the expense of an exploration of the wounds occasioned by the body and the political value of situated identities. He shows how authors such as Haraway, Grosz and Bradotti exemplify a flight from the messiness of disability into myth and metaphor. These writers privilege the capacity for movement and change, arguing for a wilful effacement of the boundary between nature and culture, fact and fiction. Abstract identities, rather

than hard-won standpoints, thus become ciphers in constant negotiation. Dorn accuses these poststructuralist feminists as consistently neglecting the role that disability typologies have played in “demonstrating” normative framings of the body politic. For example, Grosz rules out the lives of the “banal disabled” in her writings. She rationalises this by the fact that they do not elicit the same response of simultaneous horror and fascination as found with ‘real’ freaks. Grosz’s idealisation of freaks over the lived experience of the average disabled person serves as a striking contrast to for example, the work of Iris Marion Young (1990) whose “politics of difference” engages seriously with the psychosocial and spatial aspects of abjection - the fascination overwhelmed by revulsion elicited by exposure to any other being that challenges one’s own notion of bodily integrity. Grosz’s freaks operate as distinct genres of hybrid identity, but are abstracted from the political economic environment in which they would be forced to live and interact. For Young, deformed, disabled bodies are considered in tandem with their material environments. Abjection is experienced more than a physical phenomenon - it also plays out at a societal level to form distinctive socio-spatial topographies. Lesley, a Pakeha lady in her early fifties told me:

“I’m being victimised because of my accident. I’m not being helped to even enter society, basically, because of my disability...Because they see a disability they think your head’s a disability as well? Which really gets to me a lot. It happens often. Very much so. I can’t get a job because of my leg. I haven’t had a job for years...’84...I’m only 51 now...it’s a long time. They see that and ‘Na’. No jobs...they discriminate against the disabled. No way around it. We’re paid a pittance on a benefit. I’m now on an invalid’s benefit...because they see a disability they think the whole of you is disabled...my disability’s on my heel. Not on my head. They prefer to leave you alone. Ignore ya...tie a leg up for a week. And see how they get around. Just to come down to our level that they put us at. People

don't want to know. Personal views not respected. Goes back to the disability. [The home helps] think they can ride roughshod over you...and nobody will listen to us anyway...[they think] we should be privileged to have them in the house doing a little bit of work. I don't see why we should be privileged. It should be our right. If we can't manage to stay in our own house, it means we go into a geriatric home - at *our* age?!

In trying to understand aspects of the nature of illness and disability, I have found Young's work more helpful than poststructural feminist writings of authors such as Haraway and Grosz, because I do not believe that ill and disabled people can be easily extracted from their material environments. More than the rest of the population, ill and disabled people are constantly reminded that they are different to the rest, challenged at every turn, whether via challenges posed by the built environment or the silent (or not so silent) hostility they face in their every day lives, as Lesley does.

8.6. CONCLUSIONS.

In this chapter, I have grappled with the idea that bodies are located in and shaped through narrative and discourse, institutions, and their own corporeality. In doing so, my ideas have been influenced by many authors, for example, Foucault, Grosz and Young. These writers have studied the body at societal and individual scales and their works show that bodies are clearly situated at the intersection between discourse, institutions and corporeality. For example, for Foucault, the body is not just a focus of discourse, but constitutes the link between daily practices on the one hand and the large scale organisation of power on the other (Dreyfus and Rabinow 1982). In addition, Frank suggests that narratives are essential to the coherence of our own bodies and lives, and

that they are also vital for recognising the relations with others are grounded. He continues that among the ill, as with performance artists, narratives are fundamentally embedded (1990: 89). Narratives are but components of discursive formations. Social spaces are occupied by discourses, which have a profound effect on the construction of individuals and their identity. I have tried to show this through the narratives contained in this chapter.

The stories I heard about the body suggest that Maori narratives and experiences of the body are generally submerged under Pakeha discourses. By this I do not mean that there are 'louder' Pakeha discourses of the body, in fact, in my experience it seemed to be just the opposite. There were no obvious Pakeha discourses of the body. But it is precisely this silence which suggests to me that Pakeha people in the study tended to see their body as a natural given, not worth mentioning, unproblematic and taken for granted. It only became important and worth mentioning in times of illness or disability, as in the case of Lesley, for example. This lack of reflexivity about the body is similar to the silent discourse of 'whiteness' that I mentioned in Chapter 3. Because ethnicity is often seen as pertinent only to minority groups, the idea of a Pakeha ethnicity or of a more general 'whiteness' has, until recently, been ignored (cf. Bell 1996; Berg and Kearns 1996; Jackson 1998). Pakeha, as the dominant group in New Zealand, have not needed to define themselves in terms of their ethnicity. In the same way, discourses of the Pakeha body so far have not needed to be re-examined by Pakeha people. For Pakeha, notions of the body as a natural object whose truth will be uncovered by medical knowledge are common. Maori, however, do not necessarily rely on biomedicine to explain their bodies: they already have successful explanations and understandings of their own. (I

have also outlined some of these in this chapter and Chapter 3.) Maori understand and relate to their bodies in quite a different way to Pakeha: they regard it differently and therefore manage it differently, both in terms of tradition and ritual and with regard to illness and death. Yet Maori experiences are embedded in discourses and institutions that are largely Pakeha. Biomedical knowledge is undoubtedly important to Maori, but so are other issues, such as the correct procedure for dealing with body parts that have been surgically removed, or in dealing with a person who has died. Discourses of the body highlight the operation of a politics of difference. The interweaving of power, knowledge, resistance and action might be a vital step forward for the 'new' 'post-medical' geography (Parr 1998).

The body is woven into many layers of signification, through the inscriptions of meanings onto bodies - and places - by intersecting fields of discourse. The body is told, and acted out through the stories that are folded into it. These stories are never singular, or complete. However, the body itself speaks its own language - and never remains silent for long (Nast and Pile 1998: 12). The body is mobile and channelled, fluid and fixed into places. It is not only the geopolitics of the body that matter, but also the politics of connection and disconnection, of rights over the body, and of the body as a site of struggle (ibid.: 3). One cannot deny the materiality of the body but at the same time, the body is not simply the bearer of some pre-given cultural categories. It is more than a position from which to speak. Bodies change over time, spread, age, and wither, give birth, get sick and sometimes get better. They are a crucial part of ourselves as 'racialised' and gendered, healthy or ill. They are, perhaps, the most

fundamental of sites, for new interpretations of difference (including new geographies of health/illness) to arise.

CHAPTER 9. OUTCOMES AND CONCLUSIONS.

9.1. INTRODUCTION.

As yet, little work within geography has examined the links between discourse, 'race'/ethnicity, health and the body. The aim of this project has been to connect rather than separate these diverse strands of inquiry. In this thesis I have therefore considered one instance of the connections between 'race', place and health in an attempt to show firstly, how 'race'/ethnicity, health and place are inextricably linked, and secondly, how investigating the discourses of 'race', place and health might also be a way of understanding different health geographies. This has involved a consideration of how discourses of power, knowledge, action and resistance, and the politics of difference, influence and shape individual and group identities, from the perspective of health.

The questions I was asking were: are discourses and practices of health implicated in the geographies of exclusion? If so, how? Attempting to answer this meant: (i) analysing the constructions and interpretations of health amongst Maori and Pakeha in a marginalised area; (ii) considering any discursive health differences between different ethnic groups, and whether these discourses were matched by practices; (iii) examining how other health systems are treated in hegemonic society; (iv) investigating whether there is a dominant discursive attitude towards health and illness, and whether it differs from other constructions of health; (v) interpreting whether these discourses serve the mechanisms by which others may become excluded from the mainstream; and

(vi) seeking out the mechanisms by which such discourses serve to exclude others in the mainstream.

These interests were set against a backdrop of several academic concerns: (i) the need for contextualised theory; (ii) the gap between policy makers and academics and (iii) the difficulties surrounding the politics of research. In addition, I hoped to show (i) the practical uses of narrative; and (ii) the beginnings of a more contextualized and refined medical geography; through (iii) an attempt at theorised action research.

In Chapter 1, I discussed different ways of conceptualising health. I also considered medical geography as a framework for understanding health issues. I concluded that the dominant approach to health and medical geography, that is biomedicine, was an unsuitable approach for me to take in this case, because it could not give me the answers to the questions I was asking. This meant I had to look further afield for literary guidance. In Chapter 2 I therefore explored the wider field of social and cultural theory, in particular, the nature of discourse, otherness and the body. I argued that otherness is a social process of identity formation and that discourses highlight the social processes of marginalisation, that is, how group identities become othered. Although otherness in the thesis focused on 'race'/ethnicity and illness, gender, and rurality were also relevant and were discussed further in Chapters 4, 6 and 8. Studying discourses of otherness, and other/othered discourses stresses the importance of *discourse* as opposed to "*attitude*" in understanding different health and health care experiences. Examining discourses produces understandings of difference which go beyond conventional groupings of social attitudes. Interpreting discourses

around health has shown how and why some discourses have become more influential than others, and how other discourses themselves become othered. Group differences are not natural 'facts'. They are made and remade in social interactions in which people identify themselves and one another. As long as group differences matter for the identification of self and others - and they certainly do in our society - it is impossible to ignore those differences in our everyday encounters.

I began to elaborate upon these ideas in Chapter 3, where I introduced the Aotearoa/New Zealand context, and a brief review of Maori and Pakeha experiences. I also examined discourses of health and ethnicity in Aotearoa/New Zealand, because by doing so, I could critically examine social constructions of disease, hegemonic and non-hegemonic discursive formations of health/illness issues, and the ways in which various cultures have used notions of disease to define social boundaries. I concluded that ethnicity and health affect each other in both positive and negative ways and the outcomes are highly context (including place) specific. The uneven distribution of power and/or access to it is detrimental to the health-status of marginalised groups for example ethnic minorities, elderly and disabled people. I also argued that the prevalence of Pakeha institutions (including health ones), are a reflection of power relations embedded within New Zealand society. However, these power relations are continually being re-negotiated, particularly since the Treaty of Waitangi has been taken seriously.

In Chapter 4, I acknowledged that social research cannot be carried out in isolation from society or the biography of the researcher. This chapter

therefore located the empirical work within the wider contexts of the Hokianga and my own circumstances. I argued that this area of Aotearoa/New Zealand is socially and culturally marginalised, largely because of its rurality and large Maori population. Because of this, it would be a good place in which to examine discourses of 'race'/ethnicity, otherness and the body. In terms of my own background of clinical and social science, I was in a privileged (and thus disadvantaged) position in that I am educated to a higher level than many of the people I was working with. This disadvantage manifested in various ways, the most common of which was that often, I struggled for the right words to use in given contexts. Moreover, on occasion, people said some very contradictory things to me, but often it was simply not appropriate at that time, to follow those comments up. The price of being tactful was probably some material lost to the project. But I think that is a fair price to pay.

In Chapter 5, I proposed how I would go about doing the empirical work for the thesis. I argued that qualitative methods such as ethnography, narrative, participation and fieldnotes were the most appropriate ways of undertaking this study, because of the need for flexibility and discretion. Chapters 6, 7 and 8 focused on the actual empirical work. In these chapters I examined (i) broad discourses of rurality, 'race' and illness; (ii) a range of issues that were specifically connected with home help; and (iii) notions of the body and embodiment. Using home help as a point of entry, I was therefore able to explore a variety of issues that connected in with home help, but were much wider than it, for example, discourses of 'race'/ethnicity, illness and the body. The stories I was told emphasised several points. Firstly, that illness is as much a social experience as it is physical. Secondly, that stories reflect cultural

presuppositions and values. Thirdly, stories are complicated by ethnicity, gender and age. Fourthly, what told is a political strategy and can be a tool for challenging the status quo.

Constructions and interpretations of health amongst Maori and Pakeha in the Hokianga differed only slightly. Most Maori seemed to base their interpretations of ill-health largely on the biomedical model, as did Pakeha. Both Maori and Pakeha drew from other discourses and interpretations as well, so that overall, although constructions and interpretations relied primarily on biomedical discourses, they were supplemented considerably with Maori and other, 'alternative' notions of health and ill-health. Similarly, there were few discursive health differences between Maori and Pakeha, the main ones being, as expected, culturally based. But again, there was no rigid distinction between Maori and Pakeha. For example, although it is a Maori custom to bury the afterbirth, at Hokianga Hospital, *all* afterbirths are buried in a specially designated area, regardless of their origin. (Of course, those who want to take their placentas and deal with them themselves are allowed to do so.) Within New Zealand society, health systems other than biomedicine are often treated as cranky adjuncts, although once again, in Hokianga, things are different. There is a much more supportive prevailing ethos. Once again, I think this is to do with the ethnic and cultural mix and mixing, and the fact that there are also many 'alternative lifestylers' in the area.

These practices remind me of a particularly memorable evening, spent in the company of academics, medical doctors and others, at the home of the Chief Executive of Hokianga Health, Bridget. It was memorable for several reasons.

Most importantly for the thesis, Judy Reinken, a health consultant for Hokianga Health raised an interesting issue. She had amassed a considerable amount of evidence that showed how in terms of health status, Pakeha in the Hokianga were much closer to Maori in the Hokianga, than to Pakeha in the rest of New Zealand. Pakeha *in* the Hokianga therefore had poorer health status than Pakeha *outside* the Hokianga. On the other hand, Maori in the Hokianga had a better health status than Maori outside the Hokianga. To me, this highlighted yet again the convergence of Maori and Pakeha lives within the Hokianga, as distinct from the rest of New Zealand¹.

Marginalisation and otherness in the Hokianga is a complex mix of factors, one of which is to do with health issues. It would seem that health discourses and practices in the Hokianga are implicated in the mechanisms of exclusion from the mainstream, but this exclusion is not inevitably or always detrimental. For example, although Pakeha health status in the Hokianga is lower than in the rest of New Zealand, for Maori it is better. Moreover, as the only area-based community-owned provider of health care in New Zealand, Hokianga *is* different to the rest of the country in the way health services are organised. These issues are but two examples of a distinct local culture in the Hokianga, that to a large extent, transcends social groups. The Hokianga is

¹Less important to the thesis, but of great importance to me that night was that my master's supervisor from Canada was visiting. It was great to see him again after three years (although if I am honest, I was dreading the moment when the guitar appeared and we all had to join in the Bob Dylan repertoire!) I had other things on my mind that day too. This was the day I found out that I was pregnant. So I probably did not pay as much attention as I could have done when Judy was talking. I simply had other things on my mind.

renowned for coming together and mobilising around issues they see as important, and this particularly applies to health. One example is the fight to keep the hospital open at Rawene, in the early 1990s. Recalling this, Amy told me:

“...we fought and we fought and we did everything we could to keep that - we wrote letters of submission and everything. And when they went to the big meeting, down in Whangarei, Gwen [Principal nurse] was the only one representing *any* of the hospitals who had to have help to carry her submission letters into the meeting! But we kept our hospital because we fought for it. And that’s what we’re like in the Hokianga.”

Hokianga’s ‘difference’ is also perceived in many ways by people who do not live in the Hokianga. However, they tend to build their notions of otherness around negative aspects, such as the Hokianga’s supposed rurality, independence, anachronicity, insularity and poverty. Articles in the media are particularly influential in perpetuating these ideas (see Chapters 3 and 4).

In undertaking this research, I have also made reference to the theoretical and practical gaps between academic researchers and policy makers. What we call illness and health are both private bodily matters and public social constructs (Bair and Cayleff 1993: 13): It is well known that the lower down the social scale, the worse health status becomes, no matter how it is measured (Aggleton 1990; Davey Smith et al 1990, 1993; Hart 1985; Hayes 1994; Hayes et al 1994; Smith 1979; Townsend 1990a, 1990b; Townsend et al 1982, 1988). In the past, it has been assumed that this is somehow a direct result of poor housing, inferior nutrition, lack of education and reduced access to health services. However, new evidence suggests that it is also to do with a general

sense of powerlessness and lack of control over life circumstances (Raeburn 1994; Syme 1989). Health and well being are finely tuned to how much social, psychological and political power people have (Rosenau 1994). Societal structures which institutionalise power into the hands of a privileged sector of society are therefore demoralising and detrimental to health. The 'presence' of power, as manifested in such things as a sense of control over one's life, a sense of coherence about the world, high self-esteem and a sense of social support and community can all enhance health status (Antonovsky 1987; Steptoe and Appels 1989).

2.2. CONTRIBUTING TO CRITICAL POLICY DEBATES.

“Just as real men don't eat quiche, real educators and policy-makers don't consume and use data which are reflections of real life, personalised by project participant's opinions.” (McGee Brown, 1993: 97)

“Policy change rarely, if ever, results from the rational use of factual knowledge, though research is important in the way that it filters into the background knowledge or tacit assumptions of power holders.” (Blakemore and Boneham 1994: 10)

The main people affected by health policy and health services are not the experts, but ordinary people. Health issues and health policy therefore must be informed not solely by experts but also by ordinary people. I believe that social scientists ought to be developing a more community-based approach to health and social policy, so that health policy and action is driven by community wishes. Social scientists and policy makers should be facilitating this process, rather than controlling it (Raeburn 1994: 336-346). The above comments seem to be common reflections of prevailing attitudes in the literature. Contrary to

them, however, I found that in this instance, policy makers *did* listen to what the home help evaluation showed. At a local level, Hokianga Health were alerted to what participants were saying about home help services. They instigated some changes, and discussed others (see also Chapter 7). Moreover, once brought to the attention of the Regional Health Authority, changes were also instigated there, for example, their annual audit of the home help service in the Hokianga was cancelled (see Appendix 6). In Chapter 2, I had argued that 'giving voice' to rural others might not be enough to change configurations of power in the countryside. However, I believe that in the case of this project, in some small way, it was. Both local and regional policy makers listened to what project participants had to say, and both were prepared to act upon the evidence they were offered. Hardly revolutionary stuff (although probably highly political), but even so, encouragement that small voices and community mobilisation can effect change.

How can all this contribute to academic-policy debates? Researchers can either help or hinder in the process of community empowerment. Research can therefore be empowering, as when people are strengthened by it and can use it usefully, or disempowering, when researchers simply use subjects to their own advantage and give nothing back to the participants (see also Rosenau 1994). One example of how they may disempower communities, albeit unwittingly, is in how they characterise people and issues in health. Social science discussions of health policy often start with a broad perspective. As a result, health is often talked about in terms of readily accessible population statistics (such as morbidity and mortality) with little sense of 'real' people in the data. Health policy also tends to be formulated in these terms. As a result, 'ordinary people'

in the community tend to perceive 'the system' as dumping policies, structures and services on them in an impersonal way, without regard for their wishes and their distinctive cultural, regional and community characteristics (Raeburn 1994). Rosenau (1994) has described this as a modernistic tradition². This sort of policy development has been evident in New Zealand (Spicer et al 1994). Researchers therefore need to work with a community closely, so that community members have the opportunity to participate in all aspects of the research process. This means that they have a stake in the research: they both own and benefit from it. Throughout the evaluation, I tried not to disempower participants, by including them in as many aspects of the research process as I could. I also believe that they own the evaluation, the outcomes of which I discuss in the next section.

Agendas in health are almost entirely set by the 'experts'. Looking at power in these terms is undoubtedly disempowering from a community perspective. Lesley certainly agreed:

"I'd like them to come and do the work themselves. The highest - the snobs up in North Health? [the Regional Health Authority] Get themselves out into the community and see what they are doing to people? They don't give two hoots..."

Sibley has argued that the

"...question of making human geography radical and emancipatory [is] partly a question of getting close to other people, listening to them, making way for them. [He] would suggest that if geography is to represent difference authentically and to challenge

²I am grateful to Robin Kearns for bringing this article to my attention.

exclusionary tendencies, practitioners need to transgress disciplinary and personal boundaries and to come much closer to the people whose problems provide the primary justification for the existence of the subject...Understanding the experience of others and their relationship to place involves positioning ourselves in the world. Listening and talking with people is one necessary part of this endeavour. Reflecting on the experience in such a way that we recognise our own part in the dialogue is another." (Sibley 1995: 184-186).

In my own work, one way I have tried to address these comments is to include narrative voices, my own included, to try and decentre Eurocentric viewpoints that are inappropriate for the Hokianga context. In this way, there exists the possibility of learning *from*, and not merely simply *about*, other people, in other worlds, who speak in different voices, and who articulate different (postcolonial) positions (Gregory 1994: 189).

Health researchers may be neglecting the most important voice of all, that of the community (however defined³). In spite of assurances from

³Community can be defined as a social network of interacting individuals, usually concentrated into a defined territory (Johnston 1994: 80). However, the term is used widely and variations are many. Not all communities are territorially based, for example in the UK, ethnic groups are often referred to as communities, irrespective of whether they occupy clearly defined territories. Bell and Newby (1978) have defined community as something more than a sense of belonging to an active social network, which they refer to as 'communion'. Membership of a community involves a 'matter of custom and of shared modes of thought or expression, all of which have no other sanction than tradition'. One may belong to a community, but only becomes aware of it when it becomes threatened. Thus a community does not involve emotional ties which are characteristic of a communion. A community may stimulate such experiences and provide the context within which they develop, but all communities are not necessarily communion. The Chicago school brought these three broad definitions of community together, so that for them, a community could be a social network and/or a local social system and/or a finite bounded physical location. The Hokianga is all three of these definitions. Social Networks are tight and comprehensive; there is a strong sense of shared experiences in the

professionals of a 'community perspective', little is seen of it in practice, although admittedly, it *is* difficult for professionals to change their views of what is 'good' for people. But I believe one place to start might be in taking a view of health (and the health 'industrial complex') that is influenced much more by a genuine community perspective, that aims at a partnership relationship with the community. According to Raeburn (1994) in an ideal system, the role of health professionals would be to (i) outline possibilities to communities, (ii) to provide them data bases and information about health issues, (iii) to provide knowledge, skills, and services when required or requested by community members, particularly if they are not in a position to undertake their own activities, or do not wish to do so; and (iv) to provide support and backup for community-initiated activities. The community would have final control over the activities regarding health. Thus community members would have the opportunity to voice needs and concerns, and have the responsibility of deciding on the priorities. This may or may not be undertaken with input and negotiation from 'experts' and policy makers. Policy makers would provide the constitutional framework to enable such a system to operate, and to protect it.

Starting at a community level would mean that researchers would have to be sensitive and aware of the politics of research. From my experiences at the Asia Pacific Conference on Social Science and Medicine, (described on the first page of the thesis), I have learnt first hand that the politics of research are highly

Hokianga, and, as a former county, it has clear geographical boundaries

contested and that power and notions of 'truth' are most often held by those in positions of authority and the most vocal. In a world where funding, personal survival and autonomy of groups is at issue, the stakes are high and hard fought for. But there is much to be learnt from these experiences, least of all, self-survival. But when I was working in the Hokianga, these issues barely surfaced at all, at least explicitly. Aware of the politics of research, be they explicit or implicit, I have done my best to produce an honest evaluation and an honest thesis. And rather than put forward elitist prescriptions for change, I have tried to give people the information to act upon - what they do with it is up to them. Thus following Gubrium and Silverman (1989), who draw on Foucault, I have provided the information for participants to intervene and re-articulate discourses and practices as they wish.

2.3. OUTCOMES.

It is well known that many research projects are not made available to the participants (Pomeroy 1993: 268). Publication of results often appears in what might be obscure and/or difficult to access journals, and rarely is there a chance for oral dissemination and feedback. In my opinion, this was a community project in the sense that it involved locally connected people in a tightly bounded area (see also footnote 3, this chapter). It was therefore only proper that the results of the study were circulated back to the community. With this in mind, I was keen to make sure everybody involved in the evaluation had a chance to see what the end-product looked like, and also to contest anything they disagreed with. This was done at a presentation delivered on 23 August 1996, in St. John's Ambulance Hall, Rawene. The presentation summarised the main

findings of evaluation. All those who took part in the evaluation project were invited to attend, to hear the results and discuss further any points they wished to raise. Approximately 30 people attended, and the morning was really informal, not nearly as nerve wracking as I thought it would be - even enjoyable! After I had presented the results, there was time for a question and answer period. Here, I was asked only very specific questions relating to home help and the project, for example, how could the participants could get access to the evaluation and whether the Regional Health Authority were going to get a similar presentation. I answered all the questions honestly, and to the best of my ability. This was followed by a group discussion, about the benefits of home help, then lunch, provided by the hospital. Those attending were requested to share the results with their colleagues and neighbours; to take the findings back into their own communities and share them with others who might be interested. They were advised that the evaluation report was freely available to them, and who to contact if they wanted to look at it. Attending participants were also told about the confidentiality, ethical and legal requirements of the study: that the tapes and consent forms had to be kept for 10 years. They were given the name and address of who to contact at the University of Auckland, should they want to recover their tapes within this time period. A similar seminar was also presented to appropriate members of the Regional Health Authority and the Department of Geography at the University of Auckland, on 3 September 1996.

9.4. REFLECTIONS.

With hindsight, and in an ideal world, it is easy to say what I would have done differently. For example, I would like to have covered less ground in more

detail, but doing two things with the same information prevented me from doing that. As a result, I feel the overall project has had a two-pronged approach. I believe this acceptable, because I was honest with participants: I told them that I was doing these two things in the introductory letter (see Appendix 3). I could have undertaken the evaluation of home help and written that up for the PhD, *or* I could have gathered information that seemed pertinent to otherness, marginalisation and health issues. But I was uncomfortable about just doing the latter, because I wanted to do something that the community, or actors within the community would find useful. The choice of evaluating home help was not one I would have made myself. The commitment to meaningful research for the participants can mean you end up doing something you're not really interested in! But if I had only undertaken research that was concerned solely with issues of otherness, marginalisation and health, it would not have been particularly useful for the community, and I would have been guilty of appropriating information for my own gain. So many people in the Hokianga are simply struggling to make it through each day, I suspect that this kind of information (marginalisation and health) would have held little new material for them, even if couched in different language from that which they were used to. With hindsight, home help was an ideal point of entry from which to start. It gave me something very practical and immediate with which to work, and as conversations developed, other information was made available to me - and much more than I had hoped for. Home help therefore enabled me to pursue deeper issues as well as the immediate home help ones.

Overall, there was little that went badly. I think the worst time for me was when I was taken to task by the Maori delegates at the Third Asia-Pacific

Conference on the Social Sciences and Medicine. I have described this encounter at the very start of my thesis - it is still one of the strongest memories of my experiences of New Zealand. This was before I had even started my fieldwork! In the event, much of what they said to me, and what they said at the conference on an international platform, proved inappropriate to my experiences in the Hokianga. For example, at the conference, one of the Maori delegates, a Maori Health Senior Systems Analyst had said that teenage pregnancy in the (national) Maori community was *not* viewed as a problem, because of the *whakapapa* genealogy and its importance in Maori lives. But my research diary records the reactions of some people in Hokianga:

“This [the Maori delegates arguments] was greeted with much surprise. They were all unanimous in their agreement that this is *not so* in Northland. They pointed out that many *whanau* are out to work, and extended family might not always be available to help out. It was also suggested that this was seen as a cop-out by many. They argued that the abortion rates for Maori in Northland supported this view, although I don't know the exact numbers”.

This serves to highlight the fact that in Aotearoa/New Zealand, there is not one Maori discourse, but many. The relative success of competing discourses highlights power-knowledge constellations and how these are played out, whether on an international stage or at a local level. This is one example of where more powerful voices are able to promote their opinions to a wide audience. To a greater or lesser extent, these multiple discourses continuously shape and reflect reality. Thus there are different stories and versions of the same reality. For example, there are many discourses of health as well as numerous responses to various health initiatives.

To my mind, I have not succeeded in fully developing the links between theory and practice. This is partly because of the nature of the project. I have found it a challenge to try and get to grips with theory, and work back and forth between real experiences, real stories and real people and the theoretical literatures. In addition, much of the theory I have grappled with is not automatically applicable to the New Zealand situation. The unique experiences of New Zealanders, be they Pakeha, Maori or whatever, mean that any imported theory must be thoroughly situated, in order that it might be fruitful for research endeavours. Clearly, western discourses are permeating through New Zealand life. I have commented upon some of them in this thesis, for example, discourses of 'race'/ethnicity, diet, and illness. In carrying out this project, I have tried to be mindful of these issues (see Chapters 3, 4, 6 and 7). Although I think notions of discourse, otherness and the body synthesise well with the empirical work, I think other literatures, in particular some feminist literatures, are not really appropriate. Much of the feminist literature I was immersed in is very critical about the gendered roles of men and particularly women, arguing, for example, that there is nothing natural about women being responsible for child care and housework. Although in principal I agree with these ideas, I am not in a position to use them in much of this thesis. To do so would criticise the bedrock of Maori society, which, as a Pakeha female, is not appropriate, nor is it the aim of the thesis.

To complicate matters, although the Hokianga is viewed by other New Zealanders as a marginal area, and although residents are viewed as 'other', once immersed in the Hokianga it soon became apparent that there were countless 'others' within these 'others', and I was one of them (see also Philo 1992). Thus

to generalise about the Hokianga as other glosses over distinctions at the local level (although c.f. Kearns 1991, 1996a, 1998). Further studies would be useful, in order to explore the minutiae of narratives, discourses, institutions and practices that are operating at the local level.

On the other hand, I think the actual evaluation itself was successful. It gave the participants some of the information they were looking for and it helped Hokianga Health Enterprise Trust and the Regional Health Authority face the conflicts within some of their policies, which could then be changed. Hokianga Health also benefited by having their annual audit of home support services by the Regional Health Authority cancelled, and by having the research done by somebody who had no vested interests in the research outcomes. The fact that they now have a written account of people's opinions of the service means they can locate gaps and act upon them. But I am ever mindful of the fact that just because something is presented in an 'official report' style, doesn't mean that all the information is there. Thus this project and the home help evaluation themselves remain partial stories. Like policy narratives, the lay narratives and this narrative are partial stories too. The meaning of a text cannot be obtained simply from analysing what was said, because what was *not* said may actually be more important. The question of how to get at these differences - if indeed they should be got at remains a perplexing and unresolved issue for me.

Although many of the interviews were conducted in Maori, with a person the clients knew and trusted, I have no doubt that some narratives were going unsaid. I believe there are several reasons for this. Firstly, the amount of formalities be dealt with prior to the conversations starting put people off. The

Regional Health Authority Ethics Committee required that formal consent was signed - and participants found the form most off-putting. Secondly, because I was from the same cultural background as many of the participants, certain taken-for-granted cultural differences might not have been adequately followed up. Thirdly, the interviews were audio-taped (my "Pakeha piece of plastic") and this undoubtedly would have affected what information we collected. Furthermore, although confidentiality was assured, many people simply did not believe us. Amy, for example, is an elderly Pakeha lady, of 79, living on her own. She has lived in the Hokianga for 12 years. She exclaimed that:

"You must realise that living in a small community like this is not the same as - I start complaining about a person and what would happen? They would take her off the job probably and put in someone else. And by that time, someone else had got to know about it - because don't tell me that *anything* is kept behind closed doors in this place. Because I know everyone of them - that I know - right back to where, when and what! What you don't know and what you don't hear in a place like this - boy! They can soon blacklist you and I would certainly be on a blacklist!"

Community identity frequently marks the narratives of both women and minorities (McLintock 1995: 315) and the evidence from Hokianga narratives supports this assertion. A strong sense of community has fostered a positive feeling of identity at the individual level, which is integral to a person's self-worth, and ultimately health. The participants of this project saw themselves very firmly as part of the Hokianga, and this supports the work of Kearns in the Hokianga (1991, 1996a, 1998). Their sense of community is closely related to a positive feeling of identity, that in part revolves around owning their own health system. The Hokianga community literally link health and place, with hospital as focal point for social interaction as well as a place for biomedical and Maori

healing practices. That the health service is a vital part of the community is reflected in the following comments from Amy, a home help client, and from Elizabeth one of the Community Health Nurses:

“...they haven’t been able to close [the health system] down when they’ve closed everything [else] down. They’ve closed the post office they’ve closed the bank - and the Hokianga tends to carry on. This is *our* health system.”

“Because people here don’t get meals on wheels, they don’t get the hospice nurse, everything is dependent on the community. The resources have to come from the community. And that’s why the home help service is so important to us”.

These comments serve to show that local communities know their own needs and that each rural community is different. Therefore what works for the Hokianga will not necessarily work in another community. There is no one solution to health problems, they are localised, contextualised and highly contingent on many other factors.

I believe that a community focus is as, if not *more* pertinent to questioning health issues than a medical focus. I believe this is one of the most important ways in which medical geography, or rather the geographies of health can help us in understanding our worlds of health and illness. Looking to things traditionally outside the medical domain will bring to the fore some important health issues, and perhaps provide a way forward for ‘new’ ‘post-medical’ geographies (Parr 1998). The focus of this thesis, that is the interweaving of place, physical impairment, and the marginalised place of rural health research, is but one way of investigating new geographies of health.

APPENDIX 1: ETHICAL APPROVAL FOR THE STUDY.



Department of Geography

Faculty of Science
The University of Auckland
Private Bag 92019
Auckland, New Zealand

Human Sciences Building
10 Symonds Street, Auckland
Telephone: 64 9 - 373 7599 ext 5923
Facsimile: 64 9 - 373 7434
email: admin@geog.auckland.ac.nz

The Secretary
North Health Ethics Committees
Private Bag 92522
Wellesley Street
Auckland

25.2.96.

Dear Ms Howard,

Please find enclosed the revised application for ethical approval of my research proposal (ref 96/010). The community health worker would be for the first visit only, as pointed out in the accompanying documentation from Hoklanga Health. I have amended the ethics proposal accordingly. All other requested documentation is included. If there are any queries, please do not hesitate to contact me at the above address or at home, telephone: 630-0737. Thank you for your help,

I look forward to hearing from you soon,

Yours sincerely,

(Helen Bromley)

Application for Ethical Approval of Research

Ref No: _____

This form must be filled in in accordance with the North Health Guidelines for the Ethical Approval of Research.
Fourteen copies of the form, the proposal, and any attachments must be provided.

| | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|-----------------------|
| Project Title | | |
| Home Support Services in the Hokianga: A Qualitative Evaluation. | | |
| Investigators: | Institution/Organisation: | Department: |
| Helen Bromley | University of Auckland | Geography |
| Dr. Robin Kearns | Private Bag 92019 Auckland | |
| Principal Investigator: Helen Bromley | | |
| (If the project is part of a study being carried out in other parts of New Zealand, state also the name and centre of the coordinator.) | | |
| National Centre: | N/A | National Coordinator: |
| Contact: (if different from principal investigator) | | |
| Contact address: | | |
| As above. | | |
| Phone Contact: | | |
| Fax Contact: | | |
| Where will the research take place? (Specify hospitals/clinics etc) | | |
| In the Hokianga region, in client's homes and Rawene hospital (not interviewing inpatients, but community staff) | | |
| This study involves the use of ionising radiation, e.g. x rays and radioactive material. (If yes, refer to Guidelines, and Appendix ...) | | |
| Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> | | |
| A brief description of the proposal in lay terms must be included with your application for inclusion in the minutes. | | |
| Included <input checked="" type="checkbox"/> | | |
| I request consideration of this proposal in closed meeting. | | |
| Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> | | |
| If yes, I have included a justification for excluding the public. | | |
| <input type="checkbox"/> | | |
| What is the source of funding for the research? | | |
| Helen Bromley is in receipt of a Bristol University Postgraduate Scholarship October 1995-September 1996, and a Leverhulme Trust Study Abroad Studentship for same period. Note: If the project is to be performed on Crown Health Enterprise premises or is to use the resources - including staff - of a Crown Health Enterprise, management approval must be obtained by the investigator prior to or concurrent with submission to an ethics committee. | | |
| see letter enclosed. | | |
| Compensation declaration attached (Refer Guidelines and Appendix ...) | | |
| Yes <input type="checkbox"/> No <input checked="" type="checkbox"/> | | |

DECLARATION:

The information supplied in this application is to the best of my knowledge accurate. I have read the North Health Guidelines for the Ethical Approval of Research and clearly understand both my obligations and the rights of the subject, particularly in so far as obtaining freely given informed consent is concerned.

Signature of Principal Investigator

Helen Bromley

Date

23.1.96.

I hereby endorse this application with my approval:

Signature of Head of Department

P. H. Hocking

Date

22/1/96

Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland.

NORTH HEALTH ETHICS COMMITTEES

APPLICATION FOR ETHICAL APPROVAL OF RESEARCH

1: TITLE OF PROJECT.

Home support services in the Hokianga: A Qualitative Evaluation.

2: INVESTIGATORS.

Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland

Helen Bromley is a Registered General Nurse with nine years postgraduate clinical experience in general medicine and oncology. At the same time she has completed a BA (Hons) in the UK, an MA in Canada and is currently in New Zealand for a year, to gather data for her PhD in geography. In Canada she carried out independent research on rural health problems, particularly those faced by indigenous peoples. The findings of her MA research have been incorporated into setting up culturally appropriate health services for that research area.

Dr. Robin Kearns
Senior Lecturer
Department of Geography
University of Auckland
Private Bag 92019
Auckland

Dr. Kearns completed his PhD in 1987 and in the eight years since has published 35 research articles and has an ongoing research relationship with the Hokianga Health Enterprise Trust.

Helen Bromley
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Auckland.

3: LOCATION OF RESEARCH.

The research will be located in the Hokianga region. Actual interviews will take place at work for staff and at home for clients, at their convenience.

4: TYPE OF SUBJECTS.

All the subjects will be volunteers whose capacity to consent is not compromised. Subjects will include staff members of the Home Support Services team as well as the recipients of those services.

5: PROJECT DESCRIPTION.

5.1 Scientific Basis for the Project.

The aims of the project are to develop and contribute to the current state of knowledge of Home Support Services in the Hokianga region. Hauora Hokianga have commissioned this study, which will provide information on the following: whether the service is doing what clients/families want it to do; whether the service is doing what it says it is doing and what people paying for it think it is doing; to see if the service could be 'better'; and whether the service is good value for money. Once this study has been completed, it will be possible to proceed to a cost benefit analysis if so desired.

The study design is qualitative. It is both descriptive and analytical. It will include questions about the external environment of the organisation; the internal environment of the organisation; the home support service users; the support service environment and staff; the management and operational environment; patterns of utilisation; organisational impacts and social impacts. The goal of this qualitative evaluation is to try to understand the situation from the participant's point of view as well as the particular institutional context. This means that the study will be a case study and not necessarily generalizable to a wider context. The evaluation will describe the general environment in which it operates, address questions of who is served, what services are provided, how much it costs etc. The data will enable the Hokianga Health Enterprise Trust to demonstrate the effectiveness of the

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service, and ensure they are fulfilling their obligations both to the purchaser of the service and those who use it.

It is expected the study will proceed as follows. There will be an ongoing literature survey. Helen Bromley will move to Rawene in order to establish links with Hokianga Health Home support services staff and clients. This is being set up, facilitated and overseen by Ms. Bridget Allan, CEO Hokianga Health Enterprise Trust (see letter enclosed). The researcher, Helen Bromley will initially visit clients with a community health worker, in order to ease the process of introductions. It is envisaged that a first visit to a client would involve explanations and *possibly* consent signing, although this will most likely occur later, once the client has had time to decide whether or not they wish to participate. Information from clients will be gathered by the researcher visiting them at home at a mutually convenient date. Information from staff will be gathered during the working day at their convenience.

The interviews will be of an open and relaxed format. There is no questionnaire; rather the data being sought is what people have to say about home support services. The evaluation is aimed at programme improvement and the type of information sought will allow a process evaluation to be undertaken, where the strengths and weaknesses of the community support services programme will be assessed. Examples of the types of questions asked include the following: Can the programme be improved? What is working well and what isn't working so well? What are the reactions of the clients, staff and others to the programme? What are the things people experience that make this programme what it is? What are their perceptions about what should be changed? How are clients brought into the programme? What is the nature of staff-client interactions?

The data will be analysed to look for causes, consequences and relationships between phenomena. The types of data analysis will be analytic memos, displays and narrative or discourse analysis. Anything that is written for this research project other than direct field notes or transcriptions can be classified as analytic memos. They may range from a brief marginal comment on a transcript thorough to full-fledged analytic essay. Analytic memos are a

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way of using writing to enhance perceptions and analytic insight. Displays include matrices, flow charts and concept maps as ways of clarifying and ordering data. These are useful ways of presenting data in a form that is can be grasped as a whole. Contextual and narrative analysis will also be used to analyse data. Theories evolved from organising the narratives will be developed in interaction with, and tailored by, the understanding of the particular data being arranged. As well as looking at segments of narratives, entire narratives will be examined, in order to understand the relationship between elements in a particular text situation or sequence of events. Discourse or narrative analysis and ethnography identify relationships among different elements and their meanings for the persons involved.

These ways of qualitatively using data will be used in combination to help identify themes, develop categories, explore similarities in the data, and the relationships among them. The data and associated insights will also assist in the development of more general understandings of access to and utilisation of health and social services in an isolated rural area in New Zealand.

5.2 Subjects

Subjects are the people who are involved with home support services in the Hokianga. This includes both staff and clients of the programme as well as managers etc. As many subjects possible will be interviewed. This is the best way of getting a breadth of viewpoints. There are approximately 60 clients and 70 staff, although it is anticipated that a proportion will decline the opportunity to participate. Therefore, as the programme is already fairly small, no potential subjects will be excluded.

The subjects will be recruited through two means. Staff of the home support services staff will be given all the information at one of their monthly meetings. The clients of home support services will be identified through home support services staff, and the CEO of the Hokianga Health Enterprise Trust, Ms. Bridget Allan. Information will be given verbally to clients, by home support services staff, and the researcher, Helen Bromley. Written information is contained in the Subject Information Sheets for both clients and staff (enclosed).

Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland.

5.3 Risks and Benefits

I cannot think of any risks implicit to this research. The benefits include increased information about an area of study, qualitative community health research, which has received relatively little academic attention to date. As well as forming the data for Helen Bromley's thesis, the data will also allow the Hokianga Health Enterprise Trust to assess the quality and appropriateness of the home support services they offer.

5.4 Initiation and Termination of Project

It is hoped the project can start in early March, 1996. The researcher, Helen Bromley can only remain in New Zealand until 14 September 1996, therefore it is essential that this project is commenced as soon as possible. The expected initiation date would thus be as soon as the project has gained ethical approval. The projected termination date is 30 August 1996.

5.5 Confidentiality

Confidentiality will be preserved in the following manner. For the purposes of data analysis, subjects will be assigned a number. In the final report, there will be no possibility that subjects could be identified. No-one but Helen Bromley and Dr. Robin Kearns will have access to the tapes and transcripts. Summary data identifying the main themes and issues that emerge will be available for viewing by the Hokianga Health Enterprise Trust board members, and my thesis coordinators in the UK. Original tapes will be returned to participants (where applicable).

Access to consent forms will be limited to Helen Bromley and Dr. Robin Kearns. Audio-cassettes will be returned to participants if they wish. All other research records will be stored by Dr. Kearns in a locked cabinet on University of Auckland premises for at least ten years. Helen Bromley will keep a copy of the transcriptions to take back to the UK, in order to write-up the remainder of the project and her PhD. These will be stored in a locked cabinet at the University of Bristol. After the write-up is completed, the data in Britain will be destroyed by shredding. The originals (both tapes and transcripts) will stay

Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland.

with Dr. Kearns. If after no less than 10 years there has been no request for access to the data by the participants, the data will be destroyed by shredding.

In order to limit computer access to confidential information, the data will be stored on floppy discs only. These will be kept in a locked cabinet on University of Auckland premises.

5.6 Finance

Helen Bromley is the recipient of a Bristol University Postgraduate Scholarship and a Leverhulme Trust Study Abroad Scholarship during the period October 1995- September 1996.

Helen Bromley and Dr. Kearns have no financial interest in the project.

5.7 Radiation

Section 5.7 (Radiation) is not relevant to this research proposal.

5.8 Medicines

Section 5.8 (Medicines) is not relevant to this research proposal.

5.9 Departure from Standard Patient Management

Section 5.9 (Departure from Standard Patient Management) is not relevant to this research proposal.

5.10 Retention of Data

All research records will be stored by Dr. Kearns in a locked cabinet on University of Auckland premises for at least ten years. Helen Bromley will keep a copy of the transcriptions to take back to the UK, in order to write-up the remainder of the project and her PhD. These will be stored in a locked cabinet at the University of Bristol. After the write-up is completed, the data in Britain will be destroyed by shredding. The originals (consent forms, tapes and transcripts) will stay with Dr. Kearns. If after no less than 10 years there has

Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland.

been no request for access to the data by the participants, the data will be destroyed by shredding.



North Health

Northern Regional Health Authority
Mana Hauora A Rohe O Te Raki

91-95 Mt Eden Road

Mt Eden

Private Bag 91522

Wellesley St

Auckland

New Zealand

Ph. 64 9 357 4300

Fax: 64 9 377 4301

29 February 1996

Ms Helen Bromley
Department of Geography
University of Auckland
Private Bag 92019
Auckland

Dear Ms Bromley

**96/010 HOME SUPPORT SERVICES IN THE HOKIANGA: A QUALITATIVE
EVALUATION**

Thank you for the information as requested by North Health's Ethics Committee Y at the meeting on 14 February 1996. It has been checked by a member of the Committee

The study is approved until 1 March 1997. It is certified as not being conducted principally for the benefit of a manufacturer and will be considered for coverage under ACC.

The Committee wishes you well with your research

Yours sincerely

A handwritten signature in cursive script that reads "Ann Howard".

Ann Howard
Secretary
Ethics Committees

APPROVED by the

NORTH HEALTH
ETHICS COMMITTEE

until 1 March 1997

Secretary A Howard
Date 29 February 1996

APPENDIX 2: CARE PLANS AND ASSESSMENT FORMS.



Hauora
Hokianga
Hokianga
Health

HOME SUPPORT SERVICES

MISSION STATEMENT

The Hokianga Health Services are committed to Quality Health Care. Staff members are expected to participate in Quality Assurance Activities. Thus ensuring a high standard of continuing service for Clients both in the Hospital and Community.

Household / Attendant Care Needs Contract between Hokianga Health Services and Home Support Caregiver.

_____ for assistance to _____

Dated _____

Your allocation of Hours are/is: _____ per week.

| CARE PLAN | Daily | Weekly | Monthly |
|-----------|--------------------------|--------------------------|--------------------------|
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
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| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Concerns re delivery of service from client or caregiver to be directed to the Community Health Nurse.

Caregivers are responsible:

- a) for completion of time sheets and delivered to the Community Health Nurse for signing;
- b) notification to the Community Health Nurse of any change in health status of client(s) and/or needs;
- c) to attend relevant inservice education.

The above Care Plan is a: 1st Assessment / Review (please circle)

Signed:

Community Health Nurse Client Caregiver

GUIDELINES

ATTENDANT CARE

Bathing / Showering
Hair care
Dressing
Grooming and Personal

Catheter Care
Wound Dressing
Toileting
Bowel Care
Oral Hygiene
Foot and Skin Care
Pressure areas observation and care

Socialisation as able/or required

Passive Exercises
Medication Supervision

HOME HELP

Laundry
Bed Linen
Personal Clothing
Dried, aired, put away
Ironing

Housework
Vacuuming / sweeping
Dusting / cobwebs
Floors washed weekly
Kitchen
Bathroom
Toilet
Laundry
Porch / steps
Inside windows
Fridge
Oven / microwave

Shopping
Check food supplies
Shopping as required / needs

Meal Preparation
i.e. Daily or Weekly
- for deep freeze

Socialisation
Taking for a walk
Take shopping
Cup of tea and chat



**HAUORA HOKIANGA
HOME SUPPORT NEEDS ASSESSMENT**

HOSPITAL NUMBER

For: FRAIL ELDERLY UNDER 65 OTHER (Specify)

INSTRUCTIONS:

- 1 Complete one form for each person assessed.
- 2 Please complete every question clearly. If a problem arises indicate what this is.
- 3 For each question circle the number beside the one statement which accurately describes the patient, eg. Marital Status b) married/de facto 2
- 4 Where dates are needed please use DDMMYY format, eg. 03-07-99

SECTION A - GENERAL PROFILE

1. Client's Full Name

Surname _____ First Names _____
Address _____

Community Services Card No. _____

Expiry Date _____

Client Phone No. _____ / _____

Contact Person Phone No. _____ / _____

2. Date of Birth _____ / _____ / _____

3. Date of Assessment _____ / _____ / _____

4. Date of Referral _____ / _____ / _____

5. Other People Present YES NO

Whanau Case Consultation Needed YES NO

6. Sex Male 1
Female 2

7. Marital Status
Never married 1
Married / de facto 2
Widowed 3
Separated / divorced 4

8. Ethnic Origin
European 1
Maori 2
Pacific Islander 3
Asian 4
Other (specify) _____ 5

9. Family Situation
Has no family 1
Has no family in same region 2
Receives regular contact and concern from family 3
Has infrequent contact from family 4
Has no contact with family 5
Other (specify) _____ 6

10. Present Support YES NO
None 1 2
Spouse 1 2
Neighbour / friend 1 2
Home aid 1 2
Community Health Nurse 1 2
Meals-on-Wheels 1 2
Other (specify) _____ 1 2

11. Practical Capabilities
Manage housework 1
Cook meals 1
Manage gardens 1
Do own shopping 1
Not applicable (eg. in Rest Home) 1
Other (specify) _____ 1

12. Home Support Information Given YES

SECTION B - ASSESSMENT DETAILS

13. Contact Person/Carer Representing Client

Phone No. _____ / _____

14. Client Referred By
Client 1
GP 2
Relative 3
Acute Ward 4
Geriatric Ward 5
Rest Home 6
Department of Social Welfare 7
Other (specify) _____

15. Main Reason for Request for Initial Assessment
Special needs 1
Special change in needs 2
Changing Rest Homes 3
Subsidy required 4
Deteriorating ADL / health 5
Other (specify) _____

16. Place of Assessment
Own home 1
Relative's home 2
Friend/neighbour's home 3
Other (specify) _____

17. Present Medication (list plus dose, if possible)

18. Number of Problems Identified by Client/Whanau

SECTION C: LEVEL OF INDEPENDENCE

19. Client's Location

- Isolated 1
- Immediate neighbours 2
- Availability of transport 3
- Accessibility to home 4

Other (specify) _____ 5

20. Mobility

- Walks without aids 1
- Walks with aid of stick or walker 2
- Walks only with help of a person 3
- Walks only with help of two people 4
- Moves independently in wheelchair 5
- Bedfast, chairbound, or mainly so 6

Other (specify) _____ 7

20. Use of Toilet

- Gets to and uses toilet without help 1
- Needs reminding but manages without help 2
- Requires personal assistance 3
- Unable to use toilet 4

Other (specify) _____ 5

22. Continence (Urine)

- Continent of urine 1
- Continent when toileted regularly 2
- Indwelling catheter 3
- Occasional incontinence 4
- Incontinence of urine 5

Other (specify) _____ 6

23. Continent (Faeces)

- Continent of faeces 1
- Colostomy 2
- Incontinent of faeces 3
- Occasional incontinent of faeces 4
- Constipation 5

Other (specify) _____ 6

24. Dressing

- Able to dress fully without help 1
- Able to dress with a little help 2
- Needs help with dressing 3

Other (specify) _____ 4

25. Self Care of Appearance

- Takes care of own appearance, eg. comb hair, shave 1
- Requires some personal assistance 2
- Unable to manage at all 3

26. Showering / Bathing

- Able to without help
- Unable to without help

Other (specify) _____

27. Vision

- Can see well enough to read with or without glasses
- Reduced vision but can read large print, watch TV
- Very poor vision, may need guidance/assistance at times
- Blind or nearly blind

Other (specify) _____

28. Hearing

- Hears normal conversations without aids
- Hears well with aid
- Deafness isolates him/her from normal conversation
- Severe deafness

Other (specify) _____

29. Comprehension (of speech)

- Able to follow and understand everyday conversation without undue difficulty
- Able only to understand short simple phrases
- Apparently unable to make sense of verbal communication

Unable to assess (specify) _____

30. Memory

- No noticeable memory defect
- Loss of memory for recent events - distant memory not impaired to same extent
- Selective memory
- Loss of memory for both recent and remote events

31. Safety

- Independent
- Weekly check
- Daily check
- 24 hour supervision

Other (specify) _____

32. Orientation of Place

- No evident difficulties in finding way about home
- Sometimes mistakes surroundings
- Frequently mistakes surroundings
- Totally confused as to surroundings

33. Behaviour

- Observes accepted social standards

Inappropriate behaviour (specify) _____

34. Delusions / Hallucinations

- Absent
- Mild (irregular)
- Moderate (frequent)
- Severe (complete loss of contact with reality)

35. Mood Problems

- Usual self
- Down at times
- Mood swings
- Clinically depressed

Other (specify) _____

36. Anxiety

- No anxiety
- Mild anxiety
- Anxiety impairs function
- Agitated, incapacitated by anxiety

37. Insight

- Good
- Some insight into behaviour and it's effects
- Little insight into behaviour
- Totally lacks insight

38. Wandering

| | |
|-----------------------------------------|---|
| No wandering | 1 |
| Occasional and brief bouts of wandering | 2 |
| Persistent wandering | 3 |
| Not applicable (immobile, inactive) | 4 |

39. Night Care

| | |
|----------------------------------------------------|---|
| Needs night attention rarely or never | 1 |
| Needs night attention occasionally during the week | 2 |
| Intermittent nighttime | 3 |
| Needs attention more than once a night | 4 |

40. Medications

| | |
|--------------------------------------------------------------------------|---|
| On no prescribed medication | 1 |
| Self-medicates, i.e. keeps own pills and takes these without supervision | 2 |
| Medications require supervision / administration | 3 |
| Not applicable (policy is to supervise) | 4 |

41. In this space please make any general comments which may be of further assistance in identifying this client's needs.

42. Other Support Services Referral Made to:

43. Form Completed By (Please print)

Name

Designation

(09)

Phone Number

44. Time Required for Assessment

$\frac{1}{2}$ hr 1 hr 1 $\frac{1}{2}$ hrs 2 hrs

Other

**45. Suggested Score (1-5)

---**

46. Estimated Hours Required

a) Home Help

 per week

b) Attendant Care

 per week

CO-ORDINATOR TO COMPLETE

Name of Client:

Home Help at

 hours per week

APPROVED / NOT APPROVED

Attendant Care at

 hours per week

APPROVED / NOT APPROVED

Date of Review

Signature

 Date

Hokianga Health Services

HOME SUPPORT NEEDS ASSESSMENT LEVEL

- 0** The client does not need help from others, that is s/he is independent.
- 1** There is a health deviation (alteration), however, the person usually manages care independently, or independently with aids. While the person does not rely on help from others, they need monitoring regularly.
- 2** The client requires assistance to begin an activity or task (ie. assistance to set up supplies or equipment) or complete an activity that requires infrequent support (ie. weekly or monthly). This assistance may include reminding the client to do an activity or complete an activity that requires infrequent support (ie. weekly or monthly). This level of support recognises that the client may require professional supervision/care on a periodic basis.
- 3** The client is able to manage with some supervision/assistance, and participates in care, ie intermittent assistance is required to complete the activity or procedure (to offer encouragement or aid) but assistance is not necessary throughout the entire activity.
This level of support recognises that the client requires professional/care on a regular basis, and additional support time, particularly at night.
- 4** The client is unable to manage, needs constant supervision/assistance from one person during the entire activity or offer guidance or actual hands on care. Without the constant presence of a person the activity will not be completed. This level of support includes those older people who have an age related psychiatric disability which requires constant supervision or care to ensure the person's safety.
- 5** The client requires the constant supervision or assistance from two persons during the entire activity or it will not be completed. This level of support recognises the person who requires 24 hour professional nursing supervision and continuing medical supervision, and/or may have severe behavioural problems.

NOTES:

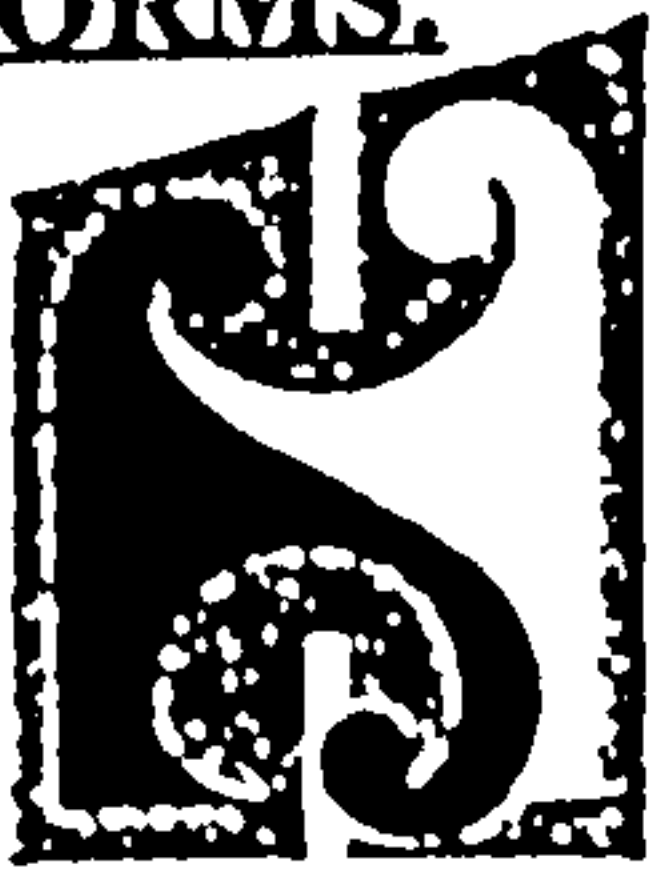
"supervision" refers to verbal encouragement and observation, not physical hands on care.

"assistance" refers to physical hands on care.

"intermittent" means that the caregiver does not have to be present during the entire activity, nor does the help have to be on a one to one basis.

The support needs levels are not intended to equate directly to particular types of care, e.g. rest home or hospital (longstay), although these will be appropriate for many at higher levels. Instead they seem to identify levels of support need which can be provided in either institutional, community, or home based settings.

APPENDIX 3: LETTERS OF INTRODUCTION AND CONSENT FORMS.



Hauora
Hoklanga

Hoklanga
Health

Hoklanga Health
Parnoll Street
Rawang
Private Bag, Kalkoho
ph: (09) 4057 709
fax: (09) 4057 707

26 March 1996

Dear

Hauora Hoklanga is responsible for providing the Home Support Services in your area. To ensure we are giving quality services, we are carrying out a survey.

An information sheet is enclosed that outlines the evaluation which will be undertaken by Helen Bromley. We would be grateful if you would sign the form below and return it in the stamped addressed envelope by Tuesday 23 April 1996. This evaluation will in no way affect the number of hours of home help which is presently allocated to you.

Should you have any queries please phone Anne Morgan or Gwen Freese at Hoklanga Hospital, phone (09) 4057 709.

This is your service, and it is important that we have your opinions, so that we can identify any areas that require improvement.

Thank you for your co-operation.

Yours sincerely

Bridget Allan
CHIEF EXECUTIVE OFFICER

enc

.....
Full Name:

I am happy for Helen to visit me

YES / NO

Do you wish an interpreter to be present?

YES / NO

(Please circle which is applicable)

Signature

Date

Hoklanga Health Enterprise Trust



Department of Geography

Faculty of Science
The University of Auckland
Private Bag 92019
Auckland, New Zealand

Human Sciences Building
10 Symonds Street, Auckland
Telephone 64 9 373 7599 ext 5923
Facsimile 64 9 373 7434
email: admin@geog.auckland.ac.nz

SUBJECT INFORMATION SHEET FOR STAFF.

Home Support Services in the Hokianga: A Qualitative Evaluation.

To: _____

My name is Helen Bromley and I am a graduate student at the University of Bristol, England, currently based at the University of Auckland. I am conducting research on community health issues for the purposes of firstly evaluating home support services in your area, and secondly as fieldwork for my thesis on health issues in rural areas.

You are invited to participate in my research and I would appreciate any assistance you can offer me between March and August 1996. As a part of my research/thesis I am doing a case study in the Hokianga, looking at how home support services operate, how things have changed over time and whether they need to be changed now (if at all). I would like to talk with as many people as I can, both clients and staff of the programme, but you are under no obligation to be interviewed. Interviews may take up half an hour to an hour and would be done at your convenience. This could be in work time or any other time you might prefer. There will be ample opportunity to talk for longer if necessary. I would prefer to audio-tape the interview but this would only be done with your consent and could be turned off at any time. The tapes will be returned to you if you would like them, at the end of the project (August 1996).

You can also withdraw information at any time. Withdrawal from the project will not affect you in any way whatsoever. If you do wish to be interviewed, please let me know by filling in a consent form and sending it to me c/o Ms. B. Allan, Hokianga Hospital. All the information you provide

is confidential and your name will not be used for any purposes. The Hoklanga Health Enterprise Trust and its employees will not have access to your details.

It is expected this research will benefit the community by producing written documentation on home support services in the Hoklanga. This information can then be used to plan for the future of the area. Some of the results will go back to the UK, helping me in my PhD thesis, which is an examination of health issues in rural areas.

Thank you very much for your time and help in making this study possible. If you have any queries or wish to know more, please phone me c/o Hoklanga Hospital 405-7791 or write to me at:

Hoklanga Health Enterprise Trust,
Private Bag,
Kalkohe.

If you prefer, you can contact either of the advisers to this project:

Dr. R. Kearns,
Department of Geography,
University of Auckland,
Private Bag 92019,
Auckland.
Tel: (09) 373-7599 extn 8442

Ms. B. Allan,
Chief Executive Officer,
Hoklanga Health Enterprise Trust,
Private Bag,
Kalkohe.
Tel: 405-7709

Or, if you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust at:

PO Box 9983,
Newmarket,
Auckland
Tel: (09) 638-9638



Department of Geography

Faculty of Science
The University of Auckland
Private Bag 92019
Auckland, New Zealand

Human Sciences Building
10 Symonds Street, Auckland
Telephone 64 9 373 7599 ext 5923
Facsimile 64 9 373 7434
email admin@geog.auckland.ac.nz

SUBJECT INFORMATION SHEET FOR CLIENTS.

Home Support Services in the Hokianga: A Qualitative Evaluation.

To: _____

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You are invited to participate in my research and I would appreciate any assistance you can offer me between March and August 1996. As a part of my research/thesis I am doing a case study in the Hokianga, looking at how home support services operate, how things have changed over time and whether they need to be changed now (if at all). I would like to talk with as many people as I can, both clients and staff of the programme, but you are under no obligation to be interviewed. Interviews may take up half an hour to an hour and would be done at your convenience. There will be ample opportunity to talk for longer if necessary. I would prefer to audio-tape the interview but this would only be done with your consent and could be turned off at any time. The tapes will be returned to you if you would like them, at the end of the project (August 1996).

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Ms. B. Allan,
Chief Executive Officer,
Hoklanga Health Enterprise Trust,
Private Bag,
Kalkohe.
Tel: 405-7709

Or, if you have any queries or concerns regarding your rights as a participant in this research you may contact the Health Advocates Trust at:

PO Box 9983,
Newmarket,
Auckland
Tel: (09) 638-9638

CONSENT FORM FOR STAFF.

Title of Project: Home support services in the Hokianga: A Qualitative Evaluation.

Principal Investigator: Helen Bromley

Name of subject: _____

| | | | |
|--------------|--------------------------------------------------------------|-----|-------|
| English: | I wish to have an interpreter | Yes | No |
| Maori: | E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau | Ae | Kao |
| Samoa: | Oute mana'o e lai se fa'amatala upu | Ioe | Leai |
| Tongan: | 'Oku fiema'u ha fakatonulea | Io | Ikal |
| Cook Island: | Ka inangaro au i tetahi tangata uri reo | Ae | Kare |
| Niuean: | Fia manako au ke fakaaoga e tagata fakahokohoko vagahau | E | Nakai |

I have heard and understood an explanation of the research project I have been invited to take part in. I have been given, and have read, a written explanation of what is asked of me, and I have had an opportunity to ask questions and to have them answered. I understand that with my permission, I will be audio-taped and that I may withdraw from the project at any time. If I do so, my work conditions and medical care will not be affected in any way. I understand that my consent to take part does not alter my legal rights.

I consent to take part as a subject in this research.

Signed: _____

I consent to the interview being audio-taped.

Signed: _____

In my opinion consent was given freely and with understanding.

_____ witness name (please print)

_____ witness signature

Date: _____

Consent obtained by: _____
Name Signature

CONSENT FORM FOR CLIENTS.

Title of Project: Home support services in the Hokianga: A Qualitative Evaluation.

Principal Investigator: Helen Bromley

Name of subject: _____

| | | | |
|--------------|--------------------------------------------------------------|-----|-------|
| English: | I wish to have an interpreter | Yes | No |
| Maori: | E hiahia ana ahau ki tetahi tangata hei korero Maori ki ahau | Ae | Kao |
| Samoan: | Oute mana'o e ial se fa'amatala upu | loe | Leal |
| Tongan: | 'Oku fiema'u ha fakatonulea | lo | ikal |
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I consent to take part as a subject in this research.

Signed: _____

I consent to the interview being audio-taped.

Signed: _____

In my opinion consent was given freely and with understanding.

_____ witness name (please print)

_____ witness signature

Date: _____

Consent obtained by: _____
Name
Signature

APPENDIX 4: TOPIC GUIDELINES.

Evaluating Home Support Services in the Hokianga: Topic Guide for Clients.

Introduction to the research: purpose and format of interview

Reassurance that they are not about to lose services

Confidentiality

Taping interviews

Check consent

Section A: What are Home Support Services?

What does that mean to you?

Do you have just home help? Or attendant care ? Or both?

What do you think might happen to you if this service didn't exist?

Section B: Seeking Services.

What?

How?

Why?

**Can you tell me about the problems and difficulties you have at home?
(Including possible transport problems)**

For instance, your disabilities and how you manage your daily routine?.

When did you start having home help and/or attendant care?

Is it easy to find out about Home Help and Attendant Care Services?

How did you find out about Home Support Services?

Remember when the nurse came to talk to you about home help? When was that? Can you tell me what happened? How was that?

The paper work - did you have to do much? Did anybody else have to do any?

Apart from the nurse, was anybody with you when you were assessed?

Would you have liked anyone to have been there when you were assessed?

Who?

Do you feel you had a chance to have your say during the assessment?

How did you come to have your particular caregiver?

Section C: Receiving Services.

Has having help at home made your difficulties better?

How long have you had your support worker?

What would you do if you didn't get on with them?

Is the service doing what you (and your family) want it to do?

What does your home support worker do for you?

Do you feel that your home support worker is the right person for the job?

Section D: Quality of Services.

How many hours a week do you have help?

How has the service helped you keep independent?

How do you feel about the services you receive?

What do you like about the service?

What do you dislike about the service?

Are your personal views respected?

(On cultural/spiritual views - need to consult with person I'm working with to work out a suitable phrasing re: Has the service recognised and respected you cultural background and beliefs?)

Given the chance, would you want to change anything about your services?

If so, what would you change?

Can you describe any gaps in the service?

Can you tell me about what YOU think are the strengths of the service?

Can you tell me about what YOU think are the weaknesses of the service?

Have you ever made a complaint? Can you describe what happened? Who did you go to? Were you satisfied?

If you haven't made a complaint, how would you go about it?

Section E: Additional Comments.

We have been talking about Home Support Services in the Hokianga, which is essentially a rural area. Do you think that that makes a difference to your experiences of being a home help?

Why does living in a rural area make a difference?

How does living in a rural area make a difference?

Do you think that living in a rural area makes a difference to your Home Support Services?

Is there anything else about Home Support Services that you would like to talk about?

Evaluating Home Support Services in the Hokianga: Topic Guide for Home Help Staff.

Introduction to the research: purpose and format of interview - this is not an evaluation of staff performance!

There are no right or wrong answers, I am simply looking for your opinions on the subject.

Confidentiality

Taping interviews

Consent

Section A: What are Home Support Services?

What information have you got about Home Support Services?

Can you describe what you think Home Support Services are?

Section B: Providing Services.

How did you get to be a home support worker?

How many clients do you have?

Do you have enough time to do all the things on your contract list?

Are you asked to do extra things that are not covered in your contract?

Are you provided with the appropriate equipment to do your job? Or do you provide your own? What sorts of things?

Do you live near them?

How far do you have to travel?

How do you actually get to the job?

Section C: Quality of Services.

Given the chance, would you want to change anything about Home Support Services in general? In particular?

Can you describe any gaps in the service?

Can you tell me about what YOU think are the strengths of the service?

Can you tell me about what YOU think are the weaknesses of the service?

Can the programme be improved? If so, how?

Section D: Work.

Have you done this sort of job before, for an organisation that is not Hauora Hokianga?

If so, what was the organisation? How different was it to what you're doing now?

Do you know anybody else in a similar sort of job? Is that in Hokianga or elsewhere?

In this job, who do you see as your boss?

Do you feel that you get enough support and/or supervision in your job from your boss?

Can you describe what training have you received for your job as home support worker?

Is there any other training you would have liked?

Do you think staff training is adequate?

What do you think staff training should include? How often do you think staff training sessions should happen?

Should they be compulsory?

Where should staff training be done?

Should you be paid to attend?

If the training is compulsory, and somebody doesn't attend, should they expect to keep their job?

How would you describe your job?

Can you describe some of the good things about your job to me? The bad things?

Section E: Additional Comments.

Is there anything else about Home Support Services that you would like to talk about?

Evaluating Home Support Services in the Hokianga: Topic Guide for Nursing Staff.

Introduction to the research: purpose and format of interview - this is not an evaluation of staff performance!

Confidentiality

Taping interviews

Consent

Section A: What are Home Support Services?

Can you describe what Home Support Services are?

Are home support services linked in with any other social programmes such as day care?

Section B: The Assessment Process.

What is the purpose of the assessment process?

How easy is it? How long does it usually take?

**When assessing needs, do you take into account the size and type of dwelling?
Any additional factors?**

What changes do you think are needed?

What are the requirements in order to get home support services?

Who is allowed to make the referral?

Is it easy to arrange all the paperwork in order to get those services?

Have you ever encountered delays when setting up home support services for a client?

Where in the process did those delays occur? Why?

How do you determine the number of hours a client needs?

Can you describe the process involved in selecting an appropriate home support worker?

Also, how do you make sure a home support worker is appropriate?

Section C: Monitoring Service Delivery.

How do you see your role in the monitoring of home support services?

What difficulties are there in this?

Do you see the need to make any changes in the monitoring role?

Section D: Quality of Services.

How do you feel about the services your clients receive?

Do you think the service is doing what it is supposed to be doing?

How are the services provided?

Do you think the structure of management affects service provision?

Can you tell me how services provided/required might differ between Maori and Pakeha?

What strategies are there for satisfying cultural needs? For clients? For staff?

What is the nature of client-staff relations? How might that affect the service?

Given the chance, what would you want to change about Home Support Services in general? In particular?

Can you describe any gaps in the service?

Can you tell me about what YOU think are the strengths and weaknesses of the service?

Can the programme be improved? If so, how?

Section E: Work.

Who would you describe as your boss?

Do you feel that you get enough support for home support assessment your boss(es)?

Can you describe some of the good things about Home Support Services to me?

The bad things?

Do you think staff training for home helps is adequate? Are there any comments you would like to make on staff training?

We have been talking about working and providing a service in what is essentially a rural area. Given that, can you elaborate on how you think the fact Hokianga is a rural area makes a difference to the nature and experience of Home Support Services?

Section F: Additional Comments.

In your opinion, are there any people who are not getting Home Support Services that should be?

Do you know why they are not receiving those services?

Is there anything else about Home Support Services that you would like to talk about?

APPENDIX 5: CLIENTS AND CARE GIVERS,
SELF-IDENTIFIED ETHNIC BACKGROUND

Table 1. Total clients.

| <u>Ethnicity</u> | <u>Male</u> | <u>Female</u> |
|-------------------------|-------------|---------------|
| Maori | 13 | 28 |
| Pacific Islander | 1 | 0 |
| Pakeha | 4 | 15 |

Table 2. Participating clients.

| <u>Ethnicity</u> | <u>Male</u> | <u>Female</u> |
|-------------------------|-------------|---------------|
| Maori | 4 | 20 |
| Pacific Islander | 1 | 0 |
| Pakeha | 1 | 12 |

Table 3. Total care givers.

| <u>Ethnicity</u> | <u>Male</u> | <u>Female</u> |
|-------------------------|--------------------|----------------------|
| Maori | 5 | 28 |
| Pacific Islander | 0 | 1 |
| Pakeha | 1 | 15 |

Table 4. Participating care givers.

| <u>Ethnicity</u> | <u>Male</u> | <u>Female</u> |
|-------------------------|--------------------|----------------------|
| Maori | 2 | 13 |
| Pacific Islander | 0 | 1 |
| Pakeha | 1 | 10 |

APPENDIX 6: CANCELLATION OF HOME HELP AUDIT.

13 Dec 1996.

Dear Helen and Jason,

It was lovely to get your card, with all the news. Sounds like things are OK right now on the job front, although not settled yet on the long term. Both Jon and I are thinking of you, and keeping our fingers crossed.

The report arrived safely, and looks fine! I've copied it to the Community Health Nurses, but given their workloads, I'm not surprised that I haven't had any

feedback yet. We've increased the hours available, and with some people dying or leaving, we now have no Home Support Waiting List! Also (take a bow!) the RHA were so impressed that they cancelled the annual audit of HSS.

Sarah says she has heard from you, and that you have some concerns about the baby. I hope everything is OK - we'll all be thinking of you over the next few



Hauora
Hoklanga
Hoklanga
Health

weeks.
Lots of love,
Bridget.

Street Address: Parnell St., Rarua
Postal Address: Private Bag, Kaitiaki
ph: (09) 4057 709
fax: (09) 4057 791

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