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PARAPLEGIC BODIES: SELF AND SOCIETY

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Sociology

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ABSTRACT

In this dissertation it is argued that humans constitute themselves as subjects in a complex of interrelationships between body, self, and society. The effects of these interrelationships are examined through the ways in which traumatic paraplegics constitute themselves as subjects following their accidents. Subsequent to paralysis there is a radical break in how paraplegics experience their bodies, in what they are physically able to do, and in the ways in which their bodies are interpreted socially, assigned meanings, and allocated space in which to do and be. Experiential accounts of paraplegia are presented as a means to exploring the implications of these changes in the ways paraplegics constitute themselves as subjects.
ACKNOWLEDGEMENTS

Firstly, and most importantly, I would like to express my gratitude to the paraplegics who so generously gave their time and selves to take part in this study. Without them the study would have no purpose or foundation. I sincerely hope that the honesty and integrity with which they responded to my questions is reflected in this dissertation.

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The question which most people eventually get around to asking me is, 'how do you think things would have been if you had not have had your accident?' It is always a difficult question to answer because how do I know what (different) paths I may have travelled over the past twenty-five years if I had not been a paraplegic? To complicate matters, the unspoken question, always barely below the surface, is 'what sort of person would you be if you were not paralysed?' This is an admission that self, the subject, subjectivity, is integral to, is shaped and formed by the body. It is difficult to be a self without being a body; we are embodied selves and enselved bodies. Humans, however, are particular types of beings, we are social bodies and social selves with the body mediating self with society and society with self.

During these interactions perceptions of self are challenged by the way others read and respond to our enselved bodies and by the ways in which they are classified by various social institutions. This is the social process by which self becomes a subject, is classified as a particular type of individual. Subjectivity is shaped by one's own perceptions of self, by one's reading of the way friends and strangers perceive self, and by their actions towards oneself. These classifications, perceptions, and actions are, however, based upon, initially at least, readings of one's body. At a personal level the subject and subjectivity is also shaped by the body, by how one experiences and lives one's body: am I/is my body fit or unfit, healthy or unhealthy, fat or thin, old, middle-aged or young, and so on. Thus, the subject is the product of complex interrelationships between body, self, and society.

Sociology and the body
It is only over the last fifteen years that a sociology of the body has emerged that allows this question to be grappled with. A text written in 1984 by Brian Turner, The Body & Society, gave much impetus to this emerging sociology of the body. In it, Turner argued that, 'any comprehensive sociology must be grounded in a recognition of the embodiment of social actors and their multiplicity as populations' (1984:1). He notes the general absence of the body in classical sociology and attributes this to the influence of Cartesian thought in sociology, the acceptance of a mind/body dichotomy and a consequent focusing on the mind as that which defines humans as social beings (ibid.:2). This was fortuitous for the emerging discipline of sociology as it allowed a clear separation of the subject area from that of
Darwinist biology and eugenics which was then the dominant explanatory paradigm for human behaviour. While the latter reduced the meaning of human behaviour to biology and physiology, sociology studied the social with an eye to uncovering the social imperative and social meaning of human behaviour. Biological determinism was rejected in favour of sociological determinism and the body in sociology became virtually absent (ibid.:31) as a number of dichotomies became entrenched in sociology: nature/society, the natural/social, biology/culture, self/society, sex/gender. The body, unfortunately, was on the wrong side of the divide.

**The body: biological or social?**

Within the sociological discourse a number of strategies have been used to subordinate biological and natural influences, especially when analysing differences between individuals and populations. These strategies included firstly, a denial of natural differences by, for example, replacing sex with gender, race with ethnicity. Secondly, by recognizing nature as important only when acting as a vehicle for culture as in Weber's interpretive sociology which emphasizes the cultural interpretation of meaningful behaviour over the actor as a biological system. Thirdly, inquiries into the domination of nature by humans tend to subordinate the biological processes involved to the sociological implications of technological change (Fox, 1993:13-15). Finally, human bodies are explained in terms of the social character of their humanness rather than in terms of fluids, tissues, and bone. This demonstrates the tendency to subordinate the biological in favour of constructing the human body according to sociological principles. In so doing a number of questions are raised about the body's status including: is the human body natural or social? Is it a biological organism or cultural artifact?

This is most evident in the sociology of health and medicine. Here the body as a biological organism is treated as an epiphenomenon to cultural imperatives. It is bracketed out and the focus shifts from the ill/diseased body to the sick role where being sick is conceived as specific social behaviour rather than malfunction of the body (Turner, 1987:39-41). Also, medical and health sociologists have directed little energy towards theorizing the diseased, dying, or dead body in favour of constructing theories around bigger questions such as the rationalization of medicine, the professionalization of medical personnel, the doctor-patient relationship, delivery systems, etc., etc. Within medical sociology, the body, *per se*, is surprisingly absent.
A sociology of the body

Bryan Turner (1984) provided the impetus for other sociologists to turn their attention to the body and the problem of developing a theory of the body. A number of theoretical and empirical studies have since been published and, when added to those already in print, form a corpus of work informing the sociology of the body. Important texts include Elias (1978), The Civilising Process; Turner (1984), The Body & Society; O'Neill (1985), Five Bodies; reviews by Frank on the sociology of the body (1990; 1991), the three volumes, Fragments for a History of the Human Body, edited by Feher, Naddaff and Tazi (1989); the collection, The Body: Social Process and Cultural Theory, edited by Featherstone, Hepworth and Turner (1991); and Shilling, (1993) The Body and Social Theory.

The timing of the emergence of the body as an object of sociological inquiry has been attributed to a number of factors. Second wave feminism beginning in the 1960s is generally taken as the starting point. Feminists focused attention on the gendered body as a profoundly social body, a site of struggle for power and control over personal integrity and societal resources; the rise of consumer culture focused attention on the body as an important site of consumption; demographic change associated with the ageing populations of Western societies has shifted attention to the elderly; technological intervention in the body (new reproductive technologies, organ transplantation) has prompted a crisis in knowing what the body actually is (Featherstone, 1983; Frank, 1990, 1991; Turner, 1984, 1987; Shilling, 1993).

Underpinning these events has been the provocative work of the French historian of ideas Michel Foucault. His project, to create a history of the modes by which human beings became subjects, centred around the body and focused upon the effects of power on bodies within specific spaces. He argued his case by showing how, when subjected to techniques of discipline, punishment, surveillance, and normalizing judgments, the body becomes a criminal in prison, a patient in hospital, a student in the classroom, and so on. While Foucault certainly never claimed to be a sociologist, his work has generated interest, sparked debate, and provoked investigations within the nascent sociology of the body. His influence is pervasive and his contribution should not be underestimated.

The absent body and the sociology of disability

Within the sociology of disability, which has emerged over the past two decades to challenge medical models of disability, the body, as with the sociology of medicine, is largely ignored.
Rather, the focus is on the social relations in which the disabled body is enmeshed. This can be attributed to the political nature of the texts. Written mostly by disabled people, they highlight the disableist and disabling nature of society and, explicitly or implicitly, agitate for civil and human rights. Equally political is the deconstruction of the medical model of disability. The medical model has at its centre the physically, sensorially, intellectually, or psychologically impaired body, couches the person entirely in terms of that deficit, and then seeks remedies to ‘cure’ or ameliorate the deficit/person. For disabled people, this not only denigrates them but it also negates disability as a possibly positive state of being. In a successful attempt to remove the focus from the disabled body, disabled theorists re-defined physical disability to account for both the biological and the social:

Impairment [is] lacking part or all of a limb, or having a defective limb, organism or mechanism of the body; and disability is the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream. (UPIAS cited in Finkelstein, 1980)

This definition shifts the locus of disability from individuals and locates it squarely in society and social organizations that discriminate. Following from this conceptualization, some writers see disability as a set of ideas, an ideology which maintains disableist structures. In this view, disability is no more or no less than ‘social oppression’. Physically impaired people are oppressed by both attitudes and the built environment which deny physical, intellectual, and emotional access to the wider social milieu. In this oppressive process people with bodily impairment are socially created as disabled people (Sullivan, 1991:260-1). In effect, this analysis follows the time honoured tradition of the sociological imperative to subordinate the biological and reconstitute the body as a social entity.

As a consequence, sociologists of disability, with the notable exception of Jenny Morris (1991:10, 70), have failed to address the body and the question of impairment. This is problematic because, in my view, an incomplete understanding of disability results. For many people with disability, their impairment has medical implications which compels them to adopt certain regimes of care without which the organism will deteriorate and die. In turn, these regimes (probably) require them to organize their lives around the care of their bodies. From

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1 Within the literature, the rule of grammar to drop the e preceding an i is not followed when spelling the terms ‘disableist’ and ‘disableism’. Given that it is mainly disabled people writing, I suspect that this form of spelling is a statement of disability pride, of disabled people naming themselves, their territory, and the structures which deny their worth and exclude them materially. Interestingly, the term ‘disabling’ follows the rule.
this perspective, disability is not only the consequence of attitudes and the built environment but also the subjective and practical experience of living an impaired body. The formulas for disabled people and disability, thus become:

\[
\text{body} + \text{disabling structures} = \text{creation of disabled people} \\
\text{or} \\
\text{bodily impairment} + \text{negative attitudes} + \text{built environment} = \text{disability}
\]

To leave the body out gives a partial and incomplete view of disability and the disabled subject.

**FOCUS OF DISSERTATION**

The main object of this dissertation is to explore the ways in which traumatic paraplegics know/create themselves following their accidents. This exploration will be guided by the questions: is there such a thing as the paraplegic subject?, is there a paraplegic subjectivity? The paraplegic body as it is experienced subjectively and socially will be central to this investigation. This will involve thinking about the paraplegic/disabled body as something which is not socially created but as a corporeality which is real and meaningful in its own right, as an indispensable element in who paraplegics are and who they become. This is not to deny the importance of the way disability is socially perceived or the individual social relations in which the paralysed body is enmeshed. Rather, it is an attempt to overcome the biology/society dichotomy that characterizes mainstream sociology; it is to affirm that the subject is both biological and social, that it is a product of body, self, and society.

*Why traumatic paraplegics?*

It is argued in this dissertation that people who live with traumatic paraplegia form a population in which the role the body plays in the constitution of self and subjectivity can be examined. It is this focus which distinguishes this study from the numerous other studies into the rehabilitation of people with paraplegia. These studies have overwhelmingly focused on how paraplegia is accommodated in a purely functional sense and the implications these
accommodations have for subsequent patterns of education, employment, income, relationships, lifestyle, and so on. This study goes a step further and examines the ways these changes affect the subject without shifting focus from the generator of these changes: the body.

Traumatic paraplegics are people who have been socialized as non-disabled people, lived and experienced non-disabled bodies, and were perceived and accepted in the wider social context as normal, able-bodied individuals. Following their accidents the way these people experience their bodies changes radically. They can no longer stand, walk, deploy their bodies as they formerly did, and, in the wider social context, their bodies are now read as disabled and the individual subject is now perceived as a disabled person with all the negative and limiting connotations this implies.

But the paraplegic body dissembles. For while it displays a high degree of disablement and is dependent upon a wheelchair for getting from A to B, the paraplegic is highly mobile and fully capable of living independently on his or her own. And since s/he has been socialized as a non-disabled person, the paraplegic subject perceives and responds to the world as such and not in a stereotypical manner which outer appearances suggest. Notwithstanding this fact, the paraplegic has to make his/her way in a society organized by and for non-disabled people, in a society in which life chances are largely dependent upon and distributed according to physical ability. Given all these factors, the question remains as to whether a new subject - the paraplegic subject - is forged in these interrelationships? That is, does a specific subjectivity, totally aligned with the corporeal experience of paraplegia, emerge? Or does the subject remain unchanged; the same person in a different body? In other words, is there such a thing as the 'paraplegic subject'? If so, what actually is it and how much is the paraplegic subject his or her body?

**Posing the questions**

In seeking answers to these questions, a two-phase study was designed in which traumatic paraplegics, who had been rehabilitated at the Otara Spinal Unit, would be given the chance to voice their life experiences in a number of areas including work history, income/economic situation, social relationships, sexuality, health and health care, leisure activities, and their experiences at the Otara Spinal Unit. Each area was divided into three sections: the situation before the accident, what had happened following the accident, and change and commentary, that is, if and how self-perception or identity and modes of cognition and operation had
changed as a result of accommodating paraplegia in this particular area of the paraplegic's life. Fifty face-to-face interviews constituted the first phase of the study. Phase two consisted of a postal survey of the remaining paraplegics in the population. The process of choosing who to interview, who to survey, the ethical issues involved and the response rate are included in Appendix 1. A copy of the questionnaire used in both phases of the study is presented in Appendix 2.

Ordering and presenting the voices
The interviews and surveys yielded a large amount of quantitative data and qualitative, experiential accounts of paraplegia. This material was coded and processed on an IBM mainframe using the SPSSx statistical package. However, it is impossible to reduce most aspects of self-perception and meaning to statistics because in so doing much of the fine detail is stripped from the process and end product. Meaning cannot always be explained by linking one facet of reality with another and then performing statistical manipulations that appear to establish a causal relationship between the two phenomena. The reality is that for paraplegics a whole cluster of phenomena contribute to the creation of meaning in any one area of existence. Qualitative accounts are most useful in illuminating this creative process.

However, having made this point, the quantitative data is useful in the form of frequency tables as illustrative of patterns of response in the entire population. As such, the quantitative data is not crucial in explaining the process of (re)constitution of the paraplegic self/subj ectivity, but is very useful in directing choice of qualitative material to be presented. For these reasons, quantitative data will not be used in the main body of the text. Instead this dissertation relies heavily on the qualitative accounts of living paraplegia by paraplegics. However, relevant quantitative data is presented in the form of frequency tables in Appendix 3.

Framing the voices
The dissertation is presented in two parts. The first provides the context for the second by examining the major ways in which Western society in general and New Zealand society in particular have understood the anomalous body, that is, physical disability. The second part presents and analyses what paraplegics said and wrote as they gave voice to the experience

2 Throughout this dissertation the term 'anomalous body' implies physical anomaly and physical disability; the terms are used interchangeably unless otherwise stated. Similarly, 'disability' and 'disabled people' always refer to physical disability unless otherwise stated.
of paraplegia and how it had shaped the ways in which they constitute themselves as subjects.

**Part One: Cultural Knowledge**

The object of Part One is to excavate the manner in which knowledge has been created around the anomalous body in Western society in an attempt to understand this perplexing phenomenon. It seems that over time accretions of meaning and practices have served to deify or demonize, reward or punish, include or isolate the anomalous body in most cultures. These inclusions and exclusions seem to be ways in which the anomalous body has been socially located so that it might be understood and dealt with. This world of meaning and practise becomes frightfully and immediately real to a person suddenly paralysed. To begin to comprehend how this impacts on subjectivity and the process of integrating body, self, and society, an understanding of the values and beliefs underpinning that social stock of knowledge about the anomalous body and disability is necessary. The first part of this dissertation excavates that knowledge, its assembly and content.

Chapter I is concerned with the conceptualization of the body, self, society, and the subject in Western society. It begins with the philosophy of Descartes, Leibnitz, and Kant which proposes a dualistic view of the subject: the rational, individual self estranged from its body and other people. As a counterpoint, the ideas of Maurice Merleau-Ponty, Karl Marx, and Michel Foucault are then examined. Here it is argued that the subject is a unified combination of biological and social factors. These ideas are particularly useful with reference to the paraplegic body as they shed light on different aspects of it. Merleau-Ponty (1962; 1963) examines the psycho-physiological aspects of the perceiving body-subject; Marx (1973; 1976; 1977) stresses the centrality of labour, that is, the physically functioning body, in the formation of the self and consciousness; while Foucault (1977; 1979; 1980; 1982) examines the impact modern institutions have on individual bodies to create individual subjects and categories of subjects.

The notion of 'the body as text' is explored in Chapter II. This involves charting the ways in which the relationship between body and self have been conceptualized in Western society. The starting point is Aristotle's treatise, *De anima*, on the relationship between the body and the soul. Later, a misreading by the scholastics of Aristotle's notion that each body has a soul which best represents its nature or character, resulted in the birth of physiognomy, the pseudo-science that claimed the ability to determine moral traits from bodily appearances. Physiognomy flourished throughout the fourteenth to eighteenth centuries with the works of
della Porta, Le Brun, and Lavatter providing scientific credence. Its impact was first felt in the Royal Courts of Europe where bodily uprightness, deportment, and civility were taken as valuable indicators of a courtier’s mana and were, as such, central to the operation of power. This *civilising process* (Elias, 1978; 1983) is briefly examined as formative in shifting attention to the body surface for an indication of social worth. In the nineteenth century, Physiognomy was reincarnated as phrenology, the reading of character from bumps on the head. The chapter closes with a discussion on the way consumerism has destabilized the ideas of the body and character in the twentieth century. The body has been turned into a project which is always in the state of becoming; a project to which self-identity and personality are intimately tied and publicly displayed by virtue of the body’s approximation to the iconic ‘body beautiful’. The form may have changed, but the basic tenets of physiognomy still underpin the reading of character or personality in the twentieth century. Today the appearances of the body are more important than ever.

In Chapters III and IV, a genealogy of disability and the disabled subject is traced via a consideration of the anomalous body. In contradistinction to the body beautiful of Chapter II, the anomalous body is examined in Chapter III in terms of its ‘monster’ and ‘freak’ status. As an object of theological and scientific investigation the anomalous body is known as a monster, a portent, a repository of knowledge. It has also been the object of commercial exploitation, exhibited to a fee paying public in Europe as ‘human marvels’ or as ‘freaks’ in the freak shows found in the amusement parlours, fairs, and circuses that travelled America until relatively recently. In both instances, less is learned about the meaning and purpose of the anomalous body than about the ways non-anomalous corporeality is understood and the need to control through objectification departures from the corporeal norm.

Chapter IV is in three sections. It is concerned with the location of the anomalous body in New Zealand society. The first section examines the ideological factors which have been formative in shaping the cultural perception of the body in Pakeha (European or non-Maori) New Zealand, namely social Darwinism and eugenics. In the second section, the modification and institutionalization of eugenic principles in New Zealand culture via the pen of Truby King and methods of the Plunket Society are scrutinized. The pivotal role played by the Plunket Society in establishing the dominant ideal as to what constitutes a ‘fit’ and ‘healthy’ body is examined in detail. The chapter concludes with a section on the process whereby anomalous bodies, as the antithesis of Plunket norms, have routinely been made subject to medical regulation, institutional care and control, and recreated as *the disabled*. 

9
Part Two: Giving Voice to the Experience of Paraplegia

In Part Two experiential accounts of various aspects of paraplegia are reproduced as a combination of paraphrasing and verbatim quotes from both interview and survey material. The honesty and integrity of the interview situation in which one paraplegic talked to another about his or her unique experience, interpretation, and process of accommodation of the shared phenomenon paraplegia, is thus captured. The use of qualitative material has the added advantage of providing the finer detail which adds flesh to the skeleton of statistics. It is used in this section to show a range of opinion and experience on many issues as well as indicating the influences and interactions which shape paraplegic self-perception and ways in which paraplegics constitute themselves as subjects.

When verbatim quotes are used the speaker's sex, age at time of accident, and length of time paralysed will be given in years in brackets at the end of the quote. These variables have been chosen because as sexed beings, humans are socialized to identify, behave, make choices, react, and have expectations that accord with a particular sex/gender. In short, one's being and life chances are overwhelmingly determined by sex and gender. Age at time of accident is given to indicate the speaker's stage of life cycle when paralysed and length of time paralysed indicates the time s/he has had to live paraplegia and integrate it into his or her being. Most importantly, this information gives the reader a sense of who is talking without knowing his or her identity. Whenever the words 'paraplegic' and 'para' (or 'paraplegics' and 'paras') are used in Part Two they refer exclusively to the paraplegics in this study unless otherwise stated.

Part Two consists of five chapters in which paraplegics give voice to experiential aspects of paraplegia and a concluding chapter in which conclusions are drawn in relation to the paraplegic subject and paraplegic subjectivity.

Chapter V focuses on the corporeal experience of paraplegia beginning with an explication of the physical and medical aspects of paraplegia. The Otara Spinal Unit is then examined as a site for the production of docile and productive bodies. Body maintenance, in terms of health and regimes of health care for the paraplegic body, is then described and analysed for the roles it plays in determining paraplegic identity and subjectivity.

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3 A number of studies (Creek et al., 1987; Trieschmann, 1988) nominate the length of time paralysed as the most crucial factor in a person's coming to terms with his or her paraplegia.
Chapter VI continues the theme of paraplegic corporeality. It begins with a discussion on movement and mobility and the implications these have for the boundaries and nature of the paraplegic body. It concludes with an exploration of the physical and social geography of the paraplegic body. This involves an examination of where and how a paraplegic can go and the social space assigned and occupied by the paraplegic body and the formative effects of these on the subject.

Chapters VII and VIII consider the social aspects of paraplegia and the implications these have for the ways in which the paraplegic body constitutes itself as subject. In Chapter VII, interactions with family, friends, and the wider community are considered along with the forms of leisure and recreation available to the paraplegic body and the implications these might have for self-perception and subjectivity. The chapter concludes with an examination of the 'paraplegic community'.

Chapter VIII looks at the socio-economic aspects of paraplegia and how these shape subjectivity. This involves an examination of the institutional arrangements for the paraplegic body in terms of compensation, income maintenance, and the labour market. This involves accounts of interactions with functionaries of the Accident Compensation Corporation and the responses from potential employers as the paraplegic body seeks paid employment. The earning power of the paraplegic body is then examined along with sources and levels of income.

Chapter IX examines the constitution of self as a subject in terms of the deployment of the paraplegic body within a gendered culture and the ways paraplegics interpreted societal perceptions and reactions to paraplegia and paraplegics. Self and the deployment of body is addressed in two parts. Part 1 focuses on the physiological effects of paraplegia on sexual function and the reproductive capabilities of paraplegics, and how these shape the ways in which male and female paraplegics constitute themselves as masculine and feminine subjects. Part 2 examines how paraplegia limits the ways in which paraplegics are able to deploy their bodies generally, and how this limits and shapes the subject positions open to them. The chapter concludes with a discussion of the various paraplegic readings of societal perceptions of paraplegia and paraplegics and the part these readings play in shaping the subject.

Chapter X concludes the dissertation with a consideration of paraplegic subjectivity and the 'I am still the same person' paradox.
PART ONE
CULTURAL KNOWLEDGE
Chapter I
SOME WAYS OF THINKING ABOUT
THE BODY, SELF, SOCIETY, AND THE SUBJECT

Towards the end of his book Missing Pieces (1982), sociologist Irving Zola asks, in effect, 'how much am I my disability and how much am I me?' He might well have asked 'how much am I my body as I experience it and how much am I my body as society experiences it?' As with Zola, I am particularly interested in people who have been forced to live different bodies from those they were born with, and the effects this has had in shaping them as subjects. The primary focus of this chapter will, thus, be the materiality of the body; the body as a real thing made up of flesh and blood, organs, tissue and fluids, muscle, and nerve fibre; the alive and living physiological body that eventually dies.

An obvious group of subjects living different bodies are those living traumatic paraplegia. I am such a person. Following paralysis there is a radical break in the ways we experience our bodies, in what we are now able to do with our bodies, and in the ways in which our bodies are reinterpreted socially, assigned meanings, and allocated space in which to do and be. At all levels body and self are torn asunder and Descartes' mind/body dualism is experienced as a reality in the following ways: the body is experienced anew, in all its alienating excess, to be managed and controlled; the how and what one does is now severely limited by the dead weight of the body; a disabled subjectivity is invariably imposed upon the paraplegic who was socialized as, and, until yesterday, treated as a non-disabled subject. The question, then, is: what kind of subject emerges from the process of integrating paralysed body, self, and society? Is it the paraplegic subject: a new totality forged out of the mind/body split, the conscious, ongoing monitoring of the body, and physical difference? Or does the subject remain essentially unchanged, that is, the same person with paraplegia?

To help in understanding these relationships it is useful to draw upon the conceptual frameworks of three writers. First, the phenomenology of Maurice Merleau-Ponty explicates the role of the lived experience of the body in the creation of self; second, Karl Marx is particularly useful in explaining how the self or consciousness is created and recreated as humans engage in the physical labour necessary to fulfil the organism's biological needs; third, Michel Foucault's discussions on disciplinary technology (1977) and bio-power (1979) show how through specific technologies of power modern society produces bodies inscribed
with particular meaning and subjectivity. Since Merleau-Ponty, Marx, and Foucault each dispute in their own particular way the dualistic view of the subject, it is useful to recapitulate the main tenets of this position.

RENAISSANCE PHILOSOPHY AND DUALISM

A dualistic world-view became deeply ingrained in Western thought through the rationalist philosophy of the Renaissance period (Burkitt, 1991). Descartes (1596-1650) argued that human experience was divided into two distinct and entirely different orders: mind and body. He believed that it was through the human capacity to think that an individual's sense of self, the 'I', was constituted. In the Second discourse (1637), he explains:

_I think, hence I am ...I thence concluded that I was a substance whose whole essence or nature consists only in thinking ...that 'l', that is to say, the mind by which I am what I am, is wholly distinct from the body ...and is such, that although the latter were not, it would still continue to be all that it is._ (emphasis in original, Descartes, 1957:27)

Here Descartes divorces the rational thought process totally from bodily or worldly experience creating what was later to become known as Cartesian Dualism. For Descartes, the human being is divided between two modes of experience: the body, functioning automatically like a machine, is the source of a mass of sensations and urges, while the rational understandings of the world are given by the mind. In dividing conscious experience from somatic experience, Descartes did not produce a unified model of the human subject containing both psychological and physiological aspects (Burkitt, 1991:5).

Leibnitz (1646-1716), with his doctrine of monadology (each individual human monad is the primary reality with all relationships mere secondary phenomena) and Kant (1724-1804), with his notion of the transcendental subject (the product of an _a priori_ rationality that cannot emerge from bodily sensations nor experience), clearly established the idea of the rational, individual self, estranged from its own emotions and from other people, a self-contained product of the mind (ibid.:4-8). Thus conceived, the subject of the rationalist philosophers poses two problems: firstly, how does the subject know/understand/relate to its own body? Secondly, since society is ultimately the setting for the collection, interaction, reproduction, and regulation of bodies (Turner, 1984:2), how is society possible if bodies are totally
divorced from rational thought processes whereby they know the world? Maurice Merleau-Ponty's thesis of the body-subject provides a compelling answer to the first question.

MAURICE MERLEAU-PONTY: THE BODY-SUBJECT

In *Phenomenology of Perception* (1962), Merleau-Ponty subjects Descartes' dualism and the classical psychological notion of the subject which rest upon this mind/body split, to rigorous philosophical critique. As he carefully explicates the body-subject, Kant's transcendental subject is also shown to be an impossibility. In Merleau-Ponty's configuration the subject has a perception because it is a body: without a body there would be no sensation, realization, or understanding of the world. Nor would there be any knowledge or perspicacity of self.

*The perceiving body: Phenomenology of perception*

There are three aspects to Merleau-Ponty's conceptualization of the body: the subject/object paradox, its spatial and temporal dimensions, the corporeal schema.

Subject/object paradox

Merleau-Ponty argues that if the body, as conceived by Descartes, was merely a mass of sensations divorced from the rational thought processes of the mind, then surely an individual would be able to dissociate him/herself from his/her body and treat it as an object. However, this is not so. The essence of objects is that they are observed as external to the observer's body who might walk around them or handle them to examine them. In contradistinction, 'my body itself is a thing which I do not observe: in order to be able to do so, I should need the use of a second body which itself would be unobservable' (Merleau-Ponty, 1962:91). In this sense, a person's body as a totality is quite mysterious to its owner (who, for example, cannot see unaided most of his/her back), yet for other people the owner's body is one hundred percent accessible/observable. And this is the great paradox of the body: for an individual the body is a subject while for others it is an object. A situation characterized by contingency, for, 'in so far as I have a body, I may be reduced to the status of an object beneath the gaze of another person, and no longer count as a person to him' (ibid.:167).

Compensation for this indignity takes the form of the individual's status as a perceiving subject whereby his/her body opens the world to him/her:
...I have a body, and through that body I am at grips with the world...knowledge of the world...is given to me with my body. (ibid.:303)

In this encounter rational thought finds its genesis:

...the world [is] conceived...as the horizon latent in all our experience and itself ever-present and anterior to every determining thought. (ibid.:92)

Moreover, being bodied gives a person access to space and time, it defines the here and now.

Spatial and temporal dimensions

For Merleau-Ponty, space can only be understood by recognizing that 'it is of the essence of space to be always 'already constituted'" (ibid.:252). Space already is. Being bodied provides the self with an anchor in space from which it gains a perspective on space and, ipso facto, the world. Moreover, embodiment gives the subject the ability to 'understand' space (ibid.:251) as a unity: rather than living space as a series of arbitrary points, the eyes order and define space in the ways objects are in relation to the subject's body. In so doing, the possibilities of an individual's physical being are established:

Besides the physical and geometrical distances which stand between myself and all things, a 'lived' distance binds all things which count and exist for me, and links them to each other. This distance measures the 'scope' of my life at every moment. (ibid.:286)

By establishing our 'lived distance', perception has important consequences for our psychological being. Referring to the distorted perceptual experience of a schizophrenic, in which the subject is joined to all objects through the power of sight and hearing, Merleau-Ponty shows the mind to be intimately linked with the bodily experience of space:

What protects the sane man against delirium or hallucination, is not his critical powers, but the structure of his space: objects remain before him...touching him only with respect. What brings about both hallucinations and myths is a shrinking in the space directly experienced, a rooting of things in our body...which is...repressed by everyday perception. (emphasis added, ibid.:291)

As the body orders space by establishing relationships with things, it also stamps the person's existence, his/her subjectivity with a temporal dimension. Being in the world delimits the present which defines the past and awaits the future. Time then, must not be seen as a succession which the subject chronicles, but as arising from:
...my relation to things. Within things themselves, the future and the past are in a kind of external state of pre-existence and survival....the future is not yet, the past is no longer, while the present ...is infinitesimal so that time collapses. (emphasis in original, ibid.:412)

It is timely to stop and consider the paraplegic body in light of Merleau-Ponty's conceptualization of the perceiving body in terms of the subject/object paradox and its spatial and temporal dimensions. For the paralysed subject, the mystery of the body increases as it becomes even less accessible visually - you see even less of your body sitting immovably in a wheelchair. This is compounded by the loss of sensory perception to the paralysed regions: what I do not see, now I cannot feel. The mystery deepens. My body as object is now more a reality to both myself and to others. The implications of this are explored in the following section.

While it would be quite erroneous to say that the paraplegic perceptual experiences of space are of the same order as that of the schizophrenic, it is important to note that space is perceived and experienced quite differently by the paralysed as opposed to the non-paralysed body. The paralysed body is now 'anchored' geographically quite differently in space; the geometrical aspects of space acquire new meaning as formally accessible 'things' become unreachable: the 'lived distance' of the paraplegic body to people and things is radically changed. The consequences of this are examined below in Chapter VI.

As with the non-paralysed body, time for the paraplegic body is still determined by my relationship to things. However, time sometimes has more meaning when calibrated in terms of 'before' and 'after' paralysis.

In the argument to date, Merleau-Ponty has established the perceiving body as the condition to objects, space, and time. It is in his discussion of internal bodily spatiality that he introduces a third term, the corporeal schema or body image. He uses this to bridge the mind-body gap enabling him to present a unified model of the subject. Moreover, Merleau-Ponty shows the corporeal schema to be a psycho-physiological mechanism through which wilful movement, bodily differentiation, and intersubjectivity become possible.

**The corporeal schema: mind/body integration**

Merleau-Ponty begins by rejecting Descartes' idea that the body is just a mass of disorganized sensations. First, I am conscious of my body as a *postural schema*, that is, its position in relation to the vertical, the horizontal, and other axes of coordinates in its
environment. Proprioceptive function is registered only on the corporeal schema, locating the body internally and externally. Second, I experience my body as a system of perception in which **interoceptive** (tactile and cenesthesic, that is, the mass of sensations that informs that subject of the state of his/her different organs and bodily functions) and **exteroceptive** (vision, hearing, and all other impressions of the external world) aspects operate in collaboration, are integrated and organized as a totality (Merleau-Ponty, 1963:117). Merleau-Ponty calls the mechanism for achieving this unity the corporeal schema.

The corporeal schema is both mental and physical, primarily neurological, and can be destroyed by brain lesion. It consists of a neurological framework, not an image or representation, but a map which organizes and unifies the body (Schilder, 1950:11) and through which a wilful body is possible. According to Merleau-Ponty, the corporeal schema furnishes one with a knowledge of the body which allows one to operate without conscious reflection on how to move. For example, in walking or in throwing a stone a whole series of actions (mechanistic movements in Descartes' schema) is conglomerated into a unified whole. Thus one does not use abstract space - I *know* where that itch is, I don't have to locate it representatively to scratch it. Just as the corporeal schema organizes interoceptive sensations, it also serves as an organizing (judging, evaluating) schema for integrating exteroceptive perceptions. It is through the body's senses that we experience the world: we see, feel, smell, taste, and hear the world. While each sense modulates different data about an object, the senses intercommunicate through the medium of the body. Here they are automatically mutually comprehensible through the 'synergy' of the corporeal schema which synthesizes them into a single perception so that:

One sees the weight of a block of cast iron which sinks in the sand... hear[s] the hardness and unevenness of cobbles in the rattle of the carriage, and we speak appropriately of a 'soft', 'dull' or 'sharp' sound. (Merleau-Ponty, 1962:230)

The corporeal schema makes reciprocity with and knowledge of the world possible:

My body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my 'comprehension'.

(ibid.:235)

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1 Merleau-Ponty's formulation owes much to the work of psychoanalysts, psychologists, physiologists, and neurologists, who were major thinkers on the body image. These included Henry Head, Henri Wallon, Guillaume, Spitz, and, especially, the neurophysiologist Paul Schilder. Merleau-Ponty uses the terms 'body image' and 'corporeal schema' interchangeably.
It is the corporeal schema's fantastic ability to expand and contract which makes the world penetrable. It never stops at the skin nor is it limited to the biological body, as in the case of a blind person finding a way using a stick:

... the world of feelable things recedes and now begins, not at the outer skin of the hand, but at the end of the stick ... the stick is no longer an object perceived by the blind man, but an instrument with which he perceives. It is a bodily auxiliary, an extension of the bodily synthesis. (emphasis in original, ibid.:152)

Thus, the ability to willfully use a tool of any sort - a pen, a prosthesis, to drive a car - is dependent upon it being incorporated into one's body image: the tool must become part of the body. This explains why the paraplegic feels violated when another arbitrarily takes control and pushes him or her up an incline without first asking. Or why a paraplegic can move at speed through a crowd without touching anyone as the corporeal schema extends and envelopes the wheelchair: body and chair are one and, just as an itch can be located without seeing it, distances are known. As soon as another person takes control, the relationship is no longer organic but mechanical - ankles are hit and toes run over - even at walking pace!

Also the various parts of the body are united by the corporeal schema into a single, complete entity. Hence, when one loses a limb, or part thereof, the body image is reluctant to let it go. This reluctance is expressed in the form of a phantom (Schilder, 1950:63) indicating that the body image functions according to laws of its own which are quite different to those of the biological body. In the case of a phantom of the arm, over time the hand comes nearer to the elbow, and may eventually seem to be growing out of the stump as the nostalgic body image catches up with the biological body (ibid.:64). To Merleau-Ponty, phantoms indicate that the body-gestalt is structured by psychological not anatomical requirements. Its laws function according to a desire, a nostalgic of wholeness and completion: the phantom limb is a kind of memorial to bodily autonomy (Merleau-Ponty, 1962:81). Perhaps this is why the emaciated anorexic sees a bloated body in the mirror: her body image has yet to catch up with the biological body. Or why the paraplegic body remembers with nostalgia the joys of running, the luxury of mud between the toes, or the sensuality of skin against skin.

**Differentiation of the body**

Merleau-Ponty addresses the question of bodily autonomy, of how the embodied subject comes to recognize itself as an integrated, bounded being, separate from, but still able to
communicate with, other subjects, in detail in his 1963 essay, 'The child’s relations with others'. One might usefully view this essay as an appendix to his earlier phenomenology, an appendix in which Merleau-Ponty draws upon the work of neurophysiologists, developmental psychologists, and psychoanalysts to 'flesh' out his phenomenological body-subject. In the process he simultaneously undermines the fallacies of Cartesian Dualism, Leibnitzian monadology, and Kant’s transcendental subject by showing that the development of the human subject is not only an integrated physiological and psychological process, but also a process which is profoundly social.

Central to Merleau-Ponty’s argument, is the child’s physiological development: it is only as the neural pathways develop that the child comes to recognize itself as a separate, bounded body, and self. In the first six months of its life a baby is ubiquitous; it cannot distinguish itself from the rest of the universe; its corporeal schema is all pervasive. Spitz calls this first period 'the stage of anonymous collectivity'. Up to three months the baby is entirely interoceptive - external perception is impossible because muscular control of the eyes is incomplete. It is part of an undifferentiated group in which there is no distinction between psyche and soma, inside and outside, I and not I, one part of the body and another, own body and mother’s body. The baby cries when someone leaves the room because it suddenly gains an 'impression of incompleteness' (Merleau-Ponty, 1963:124). At this stage neurological development is uneven - a precise perception of movement in the hands occurs before that of the feet - the body is out of kilter, it is not complete: ’the consciousness of one’s body is thus fragmentary ...at first and gradually becomes integrated; the corporeal schema becomes precise, restructured, and matured little by little’ (ibid.:123).

Between three and six months myelinization of the various neural paths connecting the mechanisms which furnish various sensory data as well as those responsible for exteroceptivity and interoceptivity takes place. However, despite this union of the interoceptive and exteroceptive domains, the baby is still not conscious of its body as a bounded totality nor of itself as a social subject. This occurs at around eight months when the child first recognizes its own image in the mirror that is, with the acquisition of what Lacan calls the 'specular image'.

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2 Or, in other words, as a subject and as an object.
Wallon had described how up to the age of eight months a child sitting on one of its parent's knee before a mirror cannot distinguish itself from either its parent or the image. It is an undifferentiated totality. However, at eight months something occurs which causes the child to do a double-take when its parent speaks. The voice is recognized as not coming from the mirror image but from the parent behind. At this point the child separates itself from the parent, and is able to perceive self as a totality. For the first time the child apprehends a completed image of her body as a totality - the body Gestalt. The child's sight, touch, and hearing are incorporated as a visual image and a boundary established between the child's body and all other bodies (ibid.:125-33). This boundary is, however, always incomplete in humans. It has 'gaps' which, in certain circumstances, result in an absence of division between self and others (ibid.:135).

Wallon argues that the body gestalt occurs as a pure act of concentration on the part of the child. But, as has just been demonstrated, the skin-bounded body-subject only comes into being as the outcome of a social process: the gestalt can only occur in the company of another. Developing the insights of Wallon, Merleau-Ponty uses Lacan, who emphasized the affective nature of the image, to show how at the moment the child recognizes its specular image as its own, it also apprehends itself as a social being. For Lacan, the appropriation of a specular image signals the transition from the interoceptive me to the 'specular I'; from the individual ego to the, essentially social, super-ego, that is, the possibility of an ideal image of oneself. A kind of alienation follows insofar as, 'there is a conflict between the me as I feel myself and the me as I see myself or as others see me' (ibid.:137). In this way the transition from a ubiquitous corporeality to a differentiated bodily being and social subject occurs, for:

The acquisition of a specular image ... bears not only on our relations of understanding but also our relations of being, with the world and with others. (emphasis in original, 1962:137)

A problem remains, however. Classical psychology is quite definite on the point that the psyche 'is what is given to only one person' (emphasis in original, ibid.:114) and would, thus, seem quite 'incommunicable'. Perhaps one might know the other psyche by decoding bodily expressions - gestures, facial expressions, words - which one witnesses? But how does one know this performing body encloses another psyche? And how can one know that the cenesthesia that informs that subject of the state of its different organs and bodily functions operates in the same manner and conveys the same messages as mine does about my body
to me? Again, a mass of sensations is as individual as the psyche; no other subject has access to those sensations, so one's bodily experience remains impenetrable to others. How then, is communication with other subjects possible?

**Intersubjectivity**

Physiologically, the corporal schema is, *mutatis mutandis*, transferable from one subject to another. Psychologically, the corporeal schema is not limited to the biological body, it extends and pervades one's immediate world, incorporating those perceptions, organizing and making them sensible to one's consciousness. One 'lives' the world simultaneously with other subjects, perceiving it intersubjectively, making the world and ourselves mutually comprehensible:

No sooner has my gaze fallen upon a living body in process of acting than the objects surrounding it immediately take on a fresh layer of significance. .... Already the other body has ceased to be a mere fragment of the world, and becomes the theatre of a certain process of elaboration ... a certain 'view' of the world. There is taking place over there a certain manipulation of things hitherto my property ... my body which perceives the body of another person, and discovers in that other body a miraculous prolongation of my own intentions, a familiar way of dealing with the world. Henceforth, as the parts of my body together comprise a system, so my body and the other person's are one whole, two sides of the one and the same phenomenon, and the anonymous existence of which my body is the ever-renewed trace henceforth inhabits both bodies simultaneously. (Merleau-Ponty, 1962:353-4)

Language allows for dialogue, the sharing of views, creating a common ground:

... my thoughts and his are interwoven into a single fabric, my words and those of my interlocutor are called forth by the state of the discussion and they are inserted into a shared operation of which neither of us is the creator. We have a dual being, where the other is for me no longer a mere bit of behaviour in my transcendental field, nor I in his; we are collaborators for each other in consummate reciprocity. Our perspectives merge into each other, and we co-exist through a common world. (ibid.:354)

Apparent in Merleau-Ponty's explication is the sociological dimension of the corporeal schema. This follows the seminal work on the body image (postural model) by Paul Schilder. In *The Image and Appearance of the Human Body*, written in 1935, Schilder stresses time and again the 'connections' between bodies, the, 'deep community between the postural models of human beings' (Schilder, 1950:44). There is a kind of combined pool of body images from which, 'we take bits of the body-image of others in the construction of our own' (ibid.:235). Thus, the body image can be seen as a functional product of the sociocultural
representation(s) of the body. It is both individually and socially produced, that is, the way others relate to my body and their own body affects the way I relate to my own body (Fallon, 1990:80).

The body image is also culturally coordinated insofar as it contains cultural beliefs. For example, if an individual agrees with the cultural belief that the body is a gift from God, it will be treated accordingly. For Schilder, this is the way an individual builds up his/her own body and then spreads it all over the world, ‘melting’ it into others. However, he warns:

...there is no collective body-image; but everyone builds his own body-image in contact with others. There is ...a constant giving and taking so that it is true many parts of body-images are common to persons who see each other, meet each other, and are in emotional relation to each other. (Schilder, 1950:273)

Emotions prise apart the ‘gaps’ in the boundaries between bodies producing the ‘syncretic sociability’ Merleau-Ponty speaks of. Syncretic sociability occurs when there is an absence of division between bodies when, for example, people laugh or cry in unison at the movies, make the same gestures at a football match simultaneously with the player-hero, or when you feel sympathy for another the distinction between the self and the other is absent. Similarly, the jealous person is unable to distinguish self from the other, can only define self in relation to what others have. Or when, in the case of mimesis (mimicry), I am invaded by the other, what Wallon calls a kind of ‘postural impregnation’ that is resolved with my body’s reproduction of the gestures, the favourite words, the conduct of those I confront. When in love, one feels the joy or pain of the other, lives one’s life in intention, enters ‘into an undivided situation with another’ (Merleau-Ponty, 1963:141-51).

These sociological insights are particularly interesting as they allow speculation on how the paralysed subject might construct his or her body as well as explain social reaction to the disabled body in general. In the first instance, the body no longer conforms to the pool of body images available to the subject to make sense of his or her body. Interoceptive aspects cease as the mass of bodily sensations that formally relayed information about the different organs and bodily functions to the subject are blocked where the spinal cord is severed. Sensation is divorced from the mind, urges are not assimilated and responded to in a unified manner. Self is no longer in control and the body transgresses all known and available images of what should be. The paraplegic body is both alien and alienating; even more

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3 Which are likely to be gendered, culture specific, and class based.
mysterious than before, it is objectified in an attempt by the subject to know and deal with this conundrum. This is reflected in the way paraplegics spoke to me about their bodies; overwhelmingly in the third person, 'the body' was characterized as an unruly stranger which needed to be tamed, controlled, domesticated. Here Descartes configuration seems correct, body appears totally divorced from self.

During the course of data collection, numerous paraplegics recounted how some former friends had been unable to cope with their paralysis and now avoided them. Perhaps something is happening at the corporeal level that explains this irrational behaviour? It has already been demonstrated that the body-image is socially and mutually created in the presence of others. It, thus, comes as a bit of a shock to be confronted by a body which, while living, is irrevocably changed and strange. Most can accommodate this change and friendships endure. However, for some, the paralysed body confronts them as an enigma, as a thing that elicits fear, dread, embarrassment. It is folded in on itself by virtue of its lack of function and prospects for action; vortex like, it sucks in life and movement rather than offering the possibility of mutual corporeal expansion. The respective corporeal schemas can no longer embrace meaningfully and the possibility for intersubjectivity ceases. This 'corporeal' explanation might explain why the response to bodies that transgress ablebodied norms to a greater degree than paraplegia does has been even more exaggerated and violent: such people have been, and still are, routinely locked away in institutions where they can be safely maintained.

To return to Merleau-Ponty’s conceptualization, it is clear that without the corporeal schema, or body image, there would be no consciousness of body, self, or sociability. Not only are interoceptive and exteroceptive perceptions harmonized and made sensible for the individual but its pervasiveness makes possible a perceptual commonality with other subjects: the basis of the social. Hence, Merleau-Ponty’s body-subject is a material being in which physiological and psychological factors are integrated, a being which in having a body is able to perceive and experience self and the world both individually and mutually with other subjects. However, in avoiding the problems of Cartesian Dualism, Leibnitz’s separated and self-contained monad, and Kant’s transcendental subject, a new problem is created: the main characteristic of the human subject seems to be passivity, with the body becoming a kind of blotting paper merely soaking up perceptions and in the process creating a subject. Merleau-Ponty’s experiential account of the lived body in the material world, while extremely useful, fails to address two important factors in the constitution of self. First, what is done by the
body, that is, the significance of physical, productive activity in meeting the requirements of life; second, what is done to the body within and by social-institutions. In the next section the ideas of Karl Marx are used to address physiological function and the implications this has for the type of subject a body becomes.

KARL MARX: BODY, LABOUR, CONSCIOUSNESS

Unlike Merleau-Ponty, Marx conceives materialism quite differently in that he posits that meaning and objects are produced through physical activity rather than experienced intersubjectively. The differences are clear in his Theses on Feuerbach, a critique of the materialist and idealist philosophy of the day:

The chief defect or all hitherto existing materialism ... is that the thing, reality, sensuousness, is conceived only in the form of the object of contemplation, but not as sensuous human activity, practice not subjectivity.... Feuerbach ... does not conceive human activity itself as objective activity.... he regards the theoretical attitude as the only genuinely human attitude.... (Marx, 1977:156)

For Marx, it is through productive activity that individuals constitute themselves as both human and subject. In The German Ideology he argues that humans, 'begin to distinguish themselves from animals as soon as they begin to produce their means of subsistence' (ibid.:161). But Marx does not simply substitute an anthropological materialism for that of Feuerbach: his is an historical materialism. Earlier, in his sixth theses, he had stressed, 'human essence is no abstraction inherent in each single individual. In its reality it is the ensemble of the social relations' (ibid.:157). In other words, each individual does not start from scratch so to speak, but inherits the values, ideas, and practices which have been forged in and by the social labour of preceding generations. It is this legacy which both enables individuals to act as well as limits their actions; humans are social beings whose consciousness reflects past and present history.

Hence, it is evident that in Marx’s materialist analysis of consciousness there are two important features: first, ideas have a materialist basis; second, it does not conceive an unthinking consciousness that mechanically reflects objective, economic conditions but a consciousness that is both dialectical and historical. That Marx rejects dualisms of any sort is evidenced by his concept of revolutionary praxis in which the classical mind/body, object/subject, thought/action, idealism/materialism dichotomies are integrated into a unified
totality. Without the conscious intervention of human subjects in the objective historical conditions the possibility for truly emancipatory social relations did not exist.

The centrality of the subjective dimension is most obvious when Marx spells out that it is the purposive character of human labour which separates it from that of the animals:

> Nature builds no machines, no locomotives, railways, electric telegraphs, self-acting mules etc....They are organs of the human brain, created by the human hand; the power of knowledge objectified. (emphasis in original, Marx, 1980:706)

It is clear that the origins of the Marxian subject are located in the body's functional ability and capacity to labour purposefully. Marx conjures up images of pure physicality when describing the labourer who, 'sets in motion the natural forces which belong to his own body, his arms, legs, head and hands' (1976:283) to appropriate nature in order to survive. But since it would be impossible for people to meet their needs individually they do so collectively. It is in the organization and activity of this social labour that humans recreate themselves by creating new needs which in turn must be met. For Marx then, human subjects must be seen as social beings whose consciousness (sense of self) is created by the purposive, productive activity they engage in and moulded by the social relations of production in which they are enmeshed.

It is through the act of labour that humans establish a connection with nature: labour 'mediates, regulates and controls the metabolism between himself and nature' (ibid.:283). So, labour is the process whereby people freely release their creative powers and energies to become more fully human subjects. But, for Marx, under capitalism the social relations of production have become contradictory with one class exploiting and appropriating the labour of another. It is under these conditions that workers are alienated in four ways: from what they produce, from how they produce, their fellow workers, and from themselves. The act of labour is thus abased, it has ceased to be free, self-creative, and self-expressive; it is forced and compulsory, undertaken not for the satisfaction of immediate needs, but exchanged for a wage to meet needs outside itself (Marx, 1977:77-87). Thus, under capitalism, the humanity-labour-nature nexus has been destroyed; labour has become highly individualized and is only/most valued if it lies outside nature and takes the narrow form of paid work (wage labour). This is most obviously apparent in the way women's work is conceived as 'natural' with the rearing of children and the attendant domestic labour (housework) going unpaid and, by virtue of this, being cast as an inferior form of labour.
It follows that in capitalist society an important component of being recognized as a fully integrated person, both individually and socially, is to be in paid work. One of the first questions we routinely ask new acquaintances is what kind of work they do and from the response locate the person subjectively and structure the rest of the interaction accordingly. Not only do we become in large-part the type of person we are because of our jobs, but the income we earn determines our lifestyle, the level of comfort in which we live, the choices we have, the degree of control we have over our lives. There is also something moral about being employed. Having a job indicates personal responsibility, playing your part, making a contribution, being a constitutive fibre in the fabric of society. A taxpayer cannot be called a bludger: taxpayer status confers a moral right to welfare if the need arises. Paid employment is for these reasons a vital part of the complex from which social-worth and, hence, a positive sense of self is assembled in contemporary society.

Capitalist hegemony has, in turn, cast unemployment as individual, personal, moral failure. Despite studies which show mass unemployment to be an important tool which is used systematically in the restructuring of capital, its effects are internalized and inscribed on individual bodies. This is evidenced by the causal connection between unemployment and increased rates of domestic violence, divorce, child abuse, crime, malnutrition, racial conflict, being clearly established in numerous reports (Brenner, 1976; Thorns and Collard, 1979; Hakim, 1982; Shirley, 1992). Further, to be unemployed is to be alienated from what Marx defined as making an individual body human, namely, the individual and social need to be engaged in socially productive labour. This is reflected in the increased rates of physical and mental ill health, attempted suicide, and, the ultimate form of alienation, suicide amongst the unemployed (Kasl, Gore and Cobb, 1975; Moser, Fox and Jones, 1984; Platt, 1984; Cook and Sharper, 1984).

How then is the conceptual framework of Karl Marx able to help in understanding the relationships between body, self, and society? First, and most importantly, is that physiological function, the way in which creative energy is deployed, what we do with our bodies, is ultimately the determining factor in how one is constituted and constitutes self as subject. It follows from Marx’s dialectic that ‘productive physical activity’ is not simply restricted to meeting the material needs of the organism but the psychological needs as well. Hence, the expression of physiological function in play, socializing, recreation etc is also an essential part of the creation of self. Paralysis, therefore, can be expected to have important implications for self not only in terms of paid employment but also in terms of rest and
recreation. If, as a direct consequence of the loss of physiological function, major reorientations in these areas of life are forced upon the paralysed body-subject, a different kind of subject could be expected to emerge as self and society are reintegrated with paralysed body.

Marx's configuration of the subject, a physiologically and psychologically integrated social being, overcomes Cartesian dualism most effectively. For Marx, the body, physiological function, the ability to labour purposively, is inseparable from consciousness: the body and self exist in dialectical relationship. Moreover, consciousness, or self, is not only influenced/formed in conjunction with fellow workers but also by one's location in the social relations of production: a person who employs labour will have a different consciousness than one who is employed for a wage. In this sense the institutional arrangements of employment impact on the body to produce certain types of economic classes of subjects. Up to this point Marx's analysis is very useful, but beyond it the work of Michel Foucault comes into its own. Especially when trying to explain the effects of other institutional arrangements on subjectivity as they impact on individual bodies. Here Foucault's finely textured analysis of the power relations between individuals and modern institutions is most rewarding.

MICHEL FOUCAULT: BODIES OF KNOWLEDGE, SUBJECTS OF POWER

Foucault's work usefully addresses the question of what is done to the body by social institutions and the implications these actions might have on the way a person is constituted as a subject. He approaches these questions through an 'analytics of power' focusing on the deployment of disciplinary technique, normalizing judgement, bio-power, and the carceral network within the modern state. His object is to create a history of the modes by which human beings are objectified and transformed into subjects (Foucault, 1982:208).

Central to this history is an analysis of the operation and relations of power in terms of techniques and technologies of discipline, surveillance, and punishment. These techniques emerged at the end of the eighteenth and beginning of the nineteenth centuries, as the focus of punishment changed from the corporal to psychological. Bodies, formally subjected to the public spectacle of torture and death, became the objects of incarceration, surveillance, and discipline. Locked in a cell the criminal cannot evade the ever present gaze of the warder, slowly the gaze is interiorized, 'to the point that he is his own overseer ...exercising ...
surveillance over, and against, himself' (Foucault, 1980:155). Reform was the goal. It was hoped a new subject might emerge from the reflective solitude of the prison cell (Foucault, 1977:11).

**Bio-power, normalization, and the carceral network**

Prisons were just one node, albeit the first, in a network of disciplinary practices that emerged in the modern period. This larger grid, of what Foucault calls 'bio-power' (1979:140), consists of various institutions - educational, industrial, military, medical, psychiatric, the police, various apparatus of the state - and constitutes a 'carceral archipelago' (Foucault, 1977:297) which transports the disciplinary practices of the penal institutions into the wider social body. The carceral operates as a unity by adhering to a common standard of 'normalizing judgement', penetrating all levels of society, examining, judging, rooting out the abnormal, prescribing fitting means to rehabilitate or to restore the norm. A fine net of disciplinary power is cast over more and more areas of life imposing:

... a whole micro-penalty of time (lateness, absences, interruptions of tasks), of activity (inattention, negligence, lack of zeal), of behaviour (impoliteness, disobedience), of speech (idle chatter, insolence), of the body ('incorrect' attitudes, irregular gestures, lack of cleanliness), of sexuality (impurity, indecency)...

So that every aspect of everyday life is made subject to a whole series of procedures designed to enforce normality:

... the slightest departures from correct behaviour [were made] subject to punishment ... each subject finds himself caught in a punishable, punishing universality. (ibid.:178)

Bio-power is, thus, directed solely at the body. It coalesces around the social body in the form of the administration of populations, and around the individual body in a variety of settings (schools, hospitals, prison etc) where it takes particular forms. The objective is to render bodies 'docile', that is a body 'that may be subjected, used, transformed and improved' (ibid.:136). This is achieved by disciplinary practices that divide the body into units and then subject those units to precise and calculated training. Hierarchical observation (surveillance), normalizing judgement, and the examination are the techniques of 'correct training' (ibid.:170-92). The end product is a disciplined subject which is efficient and productive. Productive because an effect of surveillance is to make the body an object of
knowledge and to yield a particular 'truth'; efficient because that 'truth' is inscribed on specific bodies increasing their utility, making them calculable, comprehensible, compliant.

The carceral's various institutions, organizations, and associations are the sites where bodies are compared, differentiated, hierarchized, diagnosed; where judgements are made of normality and abnormality and of appropriate methods of correction and rehabilitation to the norm. The effect of these normalizing judgements is to impose homogeneity on the social group while simultaneously objectivizing and individualizing subjects by making it possible to measure gaps and render individual differences transparent. Accordingly, the disciplinary power flowing through the carceral is not repressive but productive. Not only does it 'fabricate' the individual but also, 'it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production' (ibid.:194). Moreover, these new procedures of individualization and the concomitant production of knowledge about human subjects firmly locates the carceral network as the condition which made the human sciences historically possible (ibid.:305).

**The carceral: objectivizing and subjectivizing sites**

In contemporary society, the hospital is an important node in the carceral where 'dividing practices' objectivize the subject as either sick or healthy, curable or incurable, complete or incomplete, normal or abnormal. The medical-judges, the priests and priestesses of secular society, having assumed the right to either absolve or condemn, exercise uncontrolled power over people's bodies, their health, and their lives. When a person is paralysed his or her body becomes the object of this medical power. Removed to the hospital, or spinal unit, the various parts of the body are subjected to intense diagnosis, classification, documentation, monitoring, and discipline to render it knowable and productive, to increase the body's utility.

Now this in itself is not a bad thing, because without investing the paralysed body with specific techniques and knowledge it would quickly deteriorate and die. However, if Foucault is correct, it would be reasonable to expect that during the process of rehabilitation the body would be objectivized as paralysed and the individual subjectivized as paraplegic and the subject would come to know itself solely in these terms. Others would also come to 'know' it in these terms. During this 'ritual of truth', the paralysed body is inserted, or, rather, becomes part of the medical discourse on paraplegia which maintains the person as a particular subject, knowing and experiencing its body in a highly medicalized way, and having
the possibilities as subject constrained by the disciplinary techniques this knowledge imposes. Rehabilitation is, in short, a:

... form of power ... which categorizes the individual ... attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. (Foucault, 1982:212)

Outside the Spinal Unit it would, again, be reasonable to expect that the technical power to discipline and normalize be extended by another set of agents/judges elsewhere in the carceral network. This would mean that additional aspects of the paraplegic's body would be subjected to further objectification, classification, measurement, monitoring, and documentation by the judges of (ab)normality which are to be found everywhere: the social-worker judge, the rehabilitation-officer judge, the occupational-therapist judge, the Accident Compensation Corporation and Department of Social Welfare judges etc., etc. And given the Foucaultian analysis, one would expect the normalizing judgments imposed on the paralysed body to produce in some way, shape, or form a particular subject.

To conclude that the paralysed individual emerges from the Spinal Unit and the welfare bureaucracy as a totalized paraplegic subject is to misread Foucault's analysis of power. Such a reading implies a passivity, a complete surrender, total subjugation. However, the particular insight of Foucault's analysis is that he does not treat power as something that is 'acquired, seized, or shared', which operates in a binary fashion from the top down on increasingly limited groups. Rather, power is everywhere, 'exercised from innumerable points', it is multidirectional, it comes from below, sideways, and above, it is a general matrix of non-egalitarian and mobile force relations. Moreover:

... where there is power, there is resistance', resistance which is often 'mobile and transitory ... producing cleavages ... fracturing unities ... furrowing across individuals themselves, cutting them up and remolding [sic] them. (Foucault, 1979:96)

Later, Foucault developed this theme when he spoke of 'sub-individuals' and the fact that, '...there is always within each of us something that fights something else' (1980b:208). Does this mean that the subject, or parts of the subject, is ever anything else than the effect of power? No, according to Foucault, because resistance is always carried out within power relations:
... resistance is never in a position of exteriority in relation to power.... one is always "inside" power, there is no "escaping" it, there is no absolute outside where it is concerned, because one is subject to the law in any case? (Foucault, 1979:95)

Notwithstanding this, Foucault went on to show how resistance may be effected by developing the notion of relations of strategy. Strategy implies contestation and, 'points of insubordination which ...are a means of escape' (1982:225). This suggests that the subject is always an effect of normalizing discourses, that, '...the very self is thus fragmented into antagonistic sites of power' (Haber, 1994:105), and that in slipping from one site to another the subject is able to effect an escape from any totalizing subject position.

From this perspective, no individual subject has a single, complete, unitary self-identity. Rather, the subject has a number of subject positions4, is a fractured unity that will resist normalization from 'mobile and transitory' identity standpoints even if those various standpoints are themselves normalized subject positions.

Hence, the paralysed individual has a reference point from which to resist the normalizing regimes of medical and bureaucratic power, namely the non-paralysed self, the subject position socialized into as a non-disabled person. Given this, one would expect that from this position the subject will resist any attempts to be turned into a 'cripple', the total negation of its former able-bodiedness. The traumatic paraplegic will not become 'one of them', a cultural stereotype that used to, and probably still does, evoke fear and dread, pity and relief. To this end, a strategy of identifying as and with the non-disabled, non-paraplegic self will probably be adopted. This strategy might well shape subjectivity in a direction that denies any sense of being totally paraplegic prior to or above other subject positions the paraplegic is able to identify with.

However, to argue that the paraplegic is completely resistant to the objectifying and subjectifying effects of the carceral, would be as equally misleading as to argue the opposite. In reality, one would expect that from time to time, when confronted by obdurate, institutional power and normalizing discourse a person may feel totally paralysed, totally subjugated to

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4 From a poststructuralist perspective a number of feminist writers have developed the notion of multiple subject positions, multiple selves, or multiple identities (McTighe Musil, 1990; Kondo, 1990; Sawicki, 1991; Kennedy, Lubelska & Walsh, 1993; Haber, 1994; Munford 1995 in relation to women with disability). Arguing from this position, Kondo states that identity: '...is not a fixed "thing", it is negotiated, open, shifting, ambiguous, the result of culturally available meanings and the open-ended, power-laden enactments of these meanings in everyday situations' (Kondo, 1990:24).
his or her paraplegia. Similarly, the reality of paralysis cannot be ignored especially when confronted by an inaccessible environment (a flight of stairs, a sandy beach) or the contingencies of body maintenance. It is on these occasions that the subject cannot escape the 'law' of its body and one would expect the paraplegic subject position to fully dominate subjectivity.

SUMMARY AND CONCLUSIONS

In this chapter the ways in which various combinations of the body, self, and society coalesce in the subject have been examined. The ideas of Maurice Merleau-Ponty, Karl Marx, and Michel Foucault were counterpoised to the dualistic and asocial conceptualizations of the rationalist philosophers of the Renaissance period. Merleau-Ponty, Marx, and Foucault were chosen not because their respective works constitute a unified social theory (they do not), but precisely because their theories illuminate specific aspects of the body-self-society combinations in ways useful to our thinking about subjects living traumatic paraplegia.

Merleau-Ponty approaches the subject through the lived experience of the body, Karl Marx through physiological function and the ability to labour productively, and Foucault through the objectivized and disciplined body. These approaches are not mutually exclusive - indeed, one might wish to argue that the objectified Foucaultian subject is the lived experience of a docile body or that Marx's labouring body is the subject of capital - but provide complimentary tools for understanding the psycho-physiological and social factors in the (re)constitution of self for paralysed bodies.
Chapter II
THE BODY AS TEXT:
READING INNER SELF FROM OUTER APPEARANCES

Throughout history the body has been the point of intersection between self and society. How human beings are constituted, the relationship between the material and the spiritual dimensions, between the body and the soul, between the corporeal and character, have been the topics of incessant philosophic and theological reflection over the centuries. Following the philosophy of Aristotle in which the soul gives form to the body, one is known by one’s body; outer appearances are taken as a reflection of the inner self. From this starting point, particular body shapes acquired specific cultural values whereby the character of the person could be known. Drawing upon this stock of knowledge, the body is the point of reference whereby strangers ‘know’ each other and structure their interaction(s) accordingly. This begs a number of questions: what is the nature of the relationship between body, self, and society? how is the self constituted? does the body constitute the self, or the self the body? is the self a product of the ways in which society defines and reacts to the body? is the body a product of social and cultural forces? An exploration of how the body came to be interpreted as a window to the soul, of the relationship between the inner self and outer appearances at certain moments in Western history, follows. Three moments will be traversed in this exploration: the pre-modern/pre-capitalist epoch, the modern era of industrial capitalism, and the consumer culture of late capitalism.

THE BODY AND THE SOUL IN PRE-MODERN SOCIETY

In examining the significance of the body in pre-modern times, the ideas which dominate the social space occupied by knights and individuals of noble birth are of most interest; it is these ideas which endure. Firstly, the division of labour is not greatly advanced in medieval society; a hierarchical, God-given social order dominates. While the lord of the castle and his knights share the landscape with the peasants and the craftsmen who work for them, as well as the beggars and cripples, they occupy a different sphere; the contempt of the nobility for other classes is far more open. Secondly, as court society develops, a new social space is created in which all the vulgarity of the lower classes is erased. In both social formations the common workers are regarded as other, less than human, expendable (see Elias,
However, as the division of labour advances the interdependence between the classes increases with the ideas of the dominant group being appropriated through imitation by the subordinate classes (and thereby awarded legitimacy). In this civilizing process the 'sociogenesis' of a formalized etiquette of the body, encompassing rules of deportment and meaning, is able to be traced (ibid:xiii).

**Medieval society: uprightness and deportment**

In the age of chivalry (the high point being from the end of the eleventh to the end of the thirteenth centuries) physical strength was the first quality looked for in knights. This reflects the weaponry and fighting mode of the day with brute strength and stamina being required to swing a sword for any length of time\(^1\). A straight and upright body was taken as an indication of strength and immediate stamina. Uprightness was considered in terms of physical deportment which had a moral\(^2\) quality about it. According to Vigarello (1989), uprightness/deportment went beyond physical posture to include clothes, a certain degree of self-possession, and an attitude of humility. In the middle ages, then, uprightness was the most desirable bodily trait. Conversely, the loss of straightness and uprightness, the stigma of deformity following disablement, was the worst thing that could happen to the knight's body for, 'he [then] falls to the lowest level of public esteem' (Vigarello, 1989:149).

**Court society: uprightness and deportment tempered by civility**

In Norbert Elias’s book, *The Civilising Process* (1978), he shows how the notion of civility became the distinguishing feature of the new social formation that was established as chivalrous society faded and the unity of Christendom disintegrated in the sixteenth century. Whereas the Roman-Latin faith had provided Europe with a sense of unity, *civility* now became the symbol of Western European unity and the new social formation underpinning it, court society. Civility not only required the court nobility and courtier class to speak French, but also demanded their adherence to a formalized etiquette which generated rules of deportment for the body: how one should dress, whether one should stand or sit in the presence of another, the degree of deference one should display to another. Etiquette, the rules which governed bodily deportment and behaviour, was essential to the operation of power within court society; etiquette provided a clearly graded scale of prestige, which

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\(^1\) It is by the sword that the upper, primarily warrior class keeps the other classes dependent (Elias, 1978).

\(^2\) Morality in medieval and court society is knowledge of the manners and character of the people (Elias, 1983:106).
allowed the King by transgression to either enhance or detract from a courtier's reputation (Elias, 1983).

The specific meaning of etiquette adopted by society can be traced to a short treatise by Erasmus, *On Civility in Children*, published in 1530. Its success was instantaneous and widespread with edition after edition been published. Within two years, an English translation was published as a textbook for the education of boys. German, Czech, and French translations followed. The treatise is concerned with bodily carriage, gestures, dress, facial expressions; manners and deportment become the mark of a man, civility the expression and characteristic of court society (Elias, 1978). Civility demanded greater body-consciousness and self-scrutiny from courtiers; the meaning of the body changed as the prime requirement of (undisciplined) brute strength was superseded by those of decorum and adherence to a formalized etiquette.

Similarly, Castiglione's *The Book of the Courtier*, became essential reading for nascent courtiers anxious to define themselves in terms of courtesy and so ingratiate themselves with the powers of the court. Detailed attention is paid to the body's proper deportment which now reveals the inner self: 'The child is not to sink his head between his shoulders, as this shows arrogance; rather, he should hold himself upright effortlessly, as this shows grace. And he should not tilt his head to the side like a hypocrite except when necessary to express his meaning' (Calviac cited in Vigarello, 1989). Posture reflects a moral attitude and civility obeys social rules. Uprightness is stressed but it must be achieved without effort. It must appear to come naturally, as an intuitive part of one's breeding. The notion of 'gracefulness' is introduced and etiquette is no longer just a moral issue.

According to Vigarello (1989), the added dimension of personal hygiene was attributed to posture in sixteenth century books on manners. A child's body posture, if habitually incorrect, could result in permanent physical distortion:

> If neglected in boyhood, bodily habits of this sort become ingrained and deform the natural posture of the body. Accordingly, those who through laziness have acquired the habit of hunching their bodies are ensuring themselves a humpback which nature has not bestowed ... efforts to alter it in later life are to no avail. (Erasmus cited in Vigarello, 1989:153)

Such a 'hump' presumably interferes with the natural flow and motion of the body. Court etiquette now requires not only correct posture but also coordinated movement which is
pleasing to the eye. While Vigarello categorizes this added dimension as 'personal hygiene', the notion of physical disability is immanent. An aesthetics of the body has been introduce which stresses 'natural' physicality, posture, elegance of movement, physical ability, 'able-bodiedness'. Physical disability is defined as the antithesis of this 'natural posture', as a hunched and deformed body. For the negligent child the horror of physical deformation, of physical disability, reinforces the precept of 'uprightness'.

But rather than leaving posture to chance, Renaissance physicians prescribed the manipulation of a child's bones from the earliest moment in order that they set straight. This preventive approach was sanctioned by western medical theory and practice of the time which was underpinned by humoral theory derived from Greek medical tradition. Within this framework, the body was conceptualized as an organic system of elements (fire, earth, air, and water), qualities (heat, cold, dry, and dampness), bodily fluids or humors (blood, yellow bile, black bile, and phlegm) and temperaments associated with these humors (sanguine, melancholic, choleric, and phlegmatic) which tends towards equilibrium (Turner, 1987). Disease and ill-health was explained by an excess or dearth of humoral activity and treatment consisted of attempts to restore a balance through techniques of diet, exercise, bleeding and rest. Similarly, physical development was understood to involve a cooling and drying out of the body. Hippocrates had described the process, thus:

The child is a blend of damp and hot elements, as he is composed of them and formed in them. For what is close to birth is very humid and very warm, and develops the best.... Adult man, after his body has stopped growing, is dry and cold, as the flow of heat no longer dominates but stops, and as the body, having stopped growing, cools off. (Hippocrates cited in Vigarello, 1989:192)

From this perspective, Renaissance doctors likened the infant's body to a mass of hot and wet clay, able to be formed into the desired shape before it cooled, dried and set in its final, adult shape. The sixteenth century treatise by Soranus, lists the manipulative techniques most suitable for repositioning vertebrae or moulding the spines of newborn infants. If any signs of deformity were detected in newborn infants remedial action was applied immediately; there was no time to lose as the possibility for effective corrective action decreased as the bones dried out³. Vigarello notes that it is difficult to distinguish between shaping action and

³ This mind-set continued into the twentieth century. The remedial action for an infant's ears which were deemed to protrude excessively was to fasten them flat to the head with a bandage or adhesive plaster so that they would 'set' at the desired angle.
preventative measures in Soranus's treatise; 'straightening action' appears to have been applied indiscriminately to all infants. The foundations for uprightness of body, a prerequisite for social recognition in courtly life, had been laid (Vigarello, 1989).

However, it was not enough just to straighten the infant's bones and leave them to set in the desired way. No, the baby's body, elastic and overflowing with humors, was an unruly body. It needed to be continually monitored and corrective action needed to be applied with a patient constancy. Swaddling clothes achieved this end; they took up where manipulation had ended, correcting, holding, moulding the body; ensuring that an upright and elegant posture would be the ultimate outcome. Viewed from this vantage point, swaddling clothes constitute the first disciplinary technology applied to the body; they are an external force imposing order and discipline on the infant body.

Different techniques were required for shaping the body during childhood. By now the vertebrae had hardened but there was still room for modifying action if need be. From about the middle of the sixteenth century, the corrective corset had been available to surgeons in the treatment of children, particularly girls, who were hunched and deformed from having their bodies too tightly bound during infancy. Made from iron, the corselets were drilled with holes to reduce weight, padded for comfort and, as a concession to the growing body, changed every three months. Corsets and whalebone, the forerunners to the child's corselet, had emerged earlier in the century as a means whereby adults, mainly women, could project the correct body shape. There were, however, different motivations behind the deployment of these technologies. The former were temporary additions worn beneath clothing to define an affected silhouette or to hide bodily deformations while the latter were aimed at inducing permanent morphological change. Corsets and whalebone were the tools used by the tailor in the pursuit of the feminine aesthetics in fashion; the corselet, a metal cage, the instrument used by the surgeon for therapeutic purposes and reserved for pathology. Both reflect a new sensitivity to physical uprightness (Vigarello, 1989).

During the seventeenth century, uprightness and bearing are extended to encompass movement, or rather the control of movement. For example, table manners require children to, 'always sit straight, without moving the arms and legs' (ibid.:176); young women are urged: 'carry your head high, do not lower your chin; modesty is in your eyes, which your must know how to move in a modest fashion, and not in your chin' (ibid.); body positions and movements were prescribed for gentlemen in fencing and chivalry manuals. Activities such
as riding and fencing were opportunities for posture to be subjected to public scrutiny. A postural defect brought ridicule upon its author, for court society now demands one always 'cut a fine figure' (ibid.:177). Codes of dress, behaviour and movement, elaborated to further the art of fencing, were extended throughout court society defining elegance and proper appearance. Elegance and style, accorded greater importance than strength in court society, are achieved through controlled and disciplined movement. To this end dance is employed to set standards of excellence and as 'the foundation for an art of controlled, developed and privileged performance', teaching nascent courtiers how to 'walk well, to curtsy, to carry their bodies properly' (ibid.:179). From an early age the actor in court society is required to monitor his or her body which now must be 'filled with a self-controlled politeness' (ibid.) as rules of etiquette organize bearing and behaviour to erase all spontaneity. Appearances become all important with prestige never far from pose. Posture is pregnant with meaning; it now indicates the ability to discipline one's passions, to disguise one's emotions (Vigarello, 1989:176-84).

Aristotle, Greek mythology and physiognomy

The notion of the body as text from which character could be read was not specific to court society. Physiognomy, the pseudoscience of determining moral traits from physical characteristics, had a long history dating back to a third century BC treatise by Aristotle. The nature of the soul, or psyche, inner self, life force, and its relationship with the body had been the subject of religious and philosophic thought for centuries. Orphism, a religious movement influential in Greece during the sixth and fifth centuries BC, taught that the body constituted a temporary tomb imprisoning the superior and immortal soul for its sins; through a long series of reincarnations the soul could be purified by subjecting the body to abstinence and penance. Eventually the soul regained its former state and attained 'blissful' release. The Orphic doctrine of transmigration was retained by Pythagoras and influenced the religious thought of Plato, Aristotle's teacher. This, then, is the intellectual background to Aristotle's treatise on the relationship between body and soul, *De anima* (Hicks, 1907; Smart, 1965).

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4 The discussion of physiognomy which follows has had to be based on secondary sources because the treatises by della Porta, Le Brun, Lavater, Cruise, Wells and Spon are unavailable in New Zealand. However, the detail of these secondary sources has allowed me to extract information suitable for the project in hand.
Aristotle believed that every animal and every plant is a natural substance composed of body, which is 'matter', and soul, which is 'form'. Soul and body are not, however, two distinct things; they are two distinct aspects of the same thing:

... matter is potentiality, form actuality ... the body is the subject of matter ... the soul...substance in the sense of the form of a natural body having life potentially within it. But substance is actuality, and thus the soul is the actuality of a body. (Aristotle, 1941:II.I.412a 10-25)

The soul, thus, gives 'form' and life to 'matter'. However, not just any soul penetrates any body:

... that any soul could be clothed upon with any body - an absurd view, for each body seems to have a form and shape of its own ... each art must use its tools, each soul its body. (ibid.:I.3.407b 20-25)

The soul, thus, resides in a body of a particular kind, furnished with the means whereby the functions of the soul can be exercised. Moreover, in the Aristotelian configuration, the soul's nature is encoded in the matter of the body.

In discussing the nature of the relationship between emotions and the body, Aristotle argued that:

... all the affections of soul involve a body - passion, gentleness, fear, pity, courage, joy, loving, and hating; in all these there is a concurrent affection of the body. (ibid.:I.1.403a 16-18)

Here, Aristotle is saying that all the passions or emotion are both physical and mental. This contrasts with Descartes, who, is genuinely dualistic in ways that Aristotle emphatically is not. Descartes, thus, has to say that the emotions are mental and just happen to be caused by and to cause various physical events while Aristotle does not. Hence, for Aristotle 'the boiling blood around the heart' is part of anger; for Descartes' it would be caused by anger.

When De anima became available for scholastic inquiry in 1200 (Clouse, 1990:288), scholars were presented with a whole new series of assumptions about the body/soul relationship. It is important to note that the scholastic's reading of De anima was shaped by 1200 years of Christian dogma which held that only individual, human beings have souls. Thus, when Aristotle talks about the 'soul', he is (roughly) talking about species souls (human versus spiders or cattle) rather than individual ones (yours versus mine) of which the scholastic were
inclined. Similarly, for Aristotle, 'a person's nature' is what s/he has in common with any other person, namely, human nature, rather than an individual, personalized nature. Also, physiognomists mistakenly took Aristotle's notion of 'form' to mean (body) 'shape.' Aristotle was to famously say that if you cut off my hand, what you then have is not a hand, but just a hunk of stuff, because a piece of matter shaped a certain way is only a hand in virtue of being part of a living (informed) body. In this sense, for Aristotle, 'form' does not equal 'shape', certainly not body shape. Thus, nothing in De anima, Aristotle's text on the relationship between the body and the soul, licences anything about reading the inner self from outer appearances. Notwithstanding this, scholastic research into the relationship between the body and the soul gave rise to physiognomy, the pseudo-science which claimed the ability to divine character from bodily structure.

Reinterpreting and building on Aristotle's claim that each species body has a particular nature or 'form' of its own, della Porta updates, expands, and repackages physiognomy for consumption in court society. In the pseudo-Aristotelian treatise De physiognomonia, della Porta (1586), argues for a relationship between human appearance and temperament by drawing an analogy with animals. During classical Antiquity, animals had acquired specific moral attributes through fable; now it was just a matter of transferring those attributes to human individuals on the basis of physical approximation. For example, those resembling a bull were considered to share its deceitful, fierce and irascible nature. Similarly, those sharing the wide extremities of the lion would be hot-tempered and strong while individuals with the delicate features of the leopard would not only be proud, deceitful and scheming but also daring and fearful. Sheep are self assured; goats are lecherous; pigs are dirty and greedy and 'if a man appears similar to an animal in any of his features let him be aware that he shall behave in a similar fashion' (Della Porta cited in Magli 1989:103).

In re-presenting the physiognomic perspective that had survived in numerous Greek and Latin texts throughout the centuries, della Porta illuminates why both deportment and civility assumed such importance in court society. The obsessive, and often cruel, pursuit of the 'correct'

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5 Personal communication with Rosalind Hursthouse.

6 Where della Porta departs from Aristotle is in moving from (roughly) species--bulls, lions--to individual human beings. One could argue that from Aristotle's point of view, no human being could resemble any other animal than another human being because any human body is a picture of the human soul. What della Porta has done is keep the Aristotelian picture for all the other animals but get particular about humans. All pigs resemble each other, but some human's resemble pigs and others do not (personal communication with Rosalind Hursthouse).
physical appearance - the spinal manipulation of infants, corselets for children, the corset and whalebone for adults - is more understandable; civility, the refinement and modification of behaviour to create the right impression, exists to either enhance or confuse the messages signalled by the body. It is not surprising, therefore, that as we enter the modern era the science of physiognomy was considered a far more reliable measure of human character than civility. For those trained in physiognomy, a show of manners could not cover any defects in personality for the most intimate secrets concealed by words were indelibly etched into the body. Under the gaze of the physiognomist, a person's facial features, body structure, and overall physical appearance revealed his or her inner self.

MODERNITY, THE BODY, TRUTH, AND PHYSIOGNOMY

The seventeenth century is generally taken as the date when modern Western thought was established: Galileo's observations in the 1610s confirmed the sun-centred universe theory of Copernicus; modern philosophy began in 1641 with Descartes' new method of systematic doubt; in 1682 the mechanical worldview contained within Newtonian physics finally laid to rest the medieval worldview (Cranston, 1965). During the seventeenth century the body and its behaviour also emerged as a place where the 'truth' could be found, and physiognomics as the means to its revelation (Magli, 1989). George Turner, writing in 1641, developed a set of rules by which character could be interpreted from the nose, lips, ears, chin, pitch of the voice, lines on the forehead, number of teeth, size of the tongue, and so on. The most telling feature for Turner was the shape of the nose; it 'revealed an individual's cruelty, revengefulness, benevolence and overall degree of aggression, quarrelsomeness, and courage' (Turner cited in Finkelstein, 1991: 21). In his search for the truth, Charles Le Brun (1698) follows a more disturbing line of inquiry. Reflecting the spirit of the time, Le Brun set about classifying and cataloguing the similarities between animal and human physiognomies, creating in the process an elaborate system of cross referenced identifications. Individual forms were studied and catalogued separately. In accompanying illustrations, Le Brun eerily recombined the forms to show, for example, a horse with human eyes and human faces endowed with the eyes, eyebrows, or noses of their corresponding animals. 'Eyes and eyebrows of men, monkeys, camels, tigers, lynx, cats, foxes, pigs, rams, are arranged on various lines...ready to be joined in odd and peculiar ways in order to create monster depictions in which the fragile threshold separating humanity from animality is revealed in an unsettling way' (Magli, 1989:114).
However, it was not enough for Le Brun to merely explore the physiognomic parallels between men and animals. Driven by the urge to extract the 'truth' from the contours of the body, Le Brun used the laws of geometry to develop a procedure whereby human character and animal nature could be measured. Accordingly, the point at which the angle formed by a straight line and the eyes' axis rests upon the nose or forehead indicates passions ranging from noble to shameful (ibid:119). At this point, science is deployed to legitimate the underlying assumptions of physiognomy; a scientific measurement of outer appearances gives a far more accurate reading of inner self.

In reality, this amounts to a teleology in which known relationships are assigned a scientific measurement which in turn is used to justify the relationship. Notwithstanding, physiognomy acquires scientific status: the 'truth' revealed by physiognomy is buttressed by the objective truth of science.

**Lavater: the scientization of physiognomy**

In the second half of the eighteenth century, Johann Casper Lavater published his massive four volume work, *Essays on Physiognomy: Physiognomical Fragments, for the Promotion of Knowledge and Love of Mankind* (1775-78) (Fragments). In this treatise, Lavater presented a total system in which the intellectual and moral elements of an individual are able to be analysed from his or her physiological characteristics. Contributions by Herder and Goethe, also keen physiognomists, add authority to the text. Lavater firmly believed that everyone used physiognomy, consciously or unconsciously, in their day-to-day lives to make judgements about character from appearance. However, this was fraught with error and lacking scientific credibility, a product of the unscientific methods of earlier physiognomists, such as Aristotle and Porta, from whom he wanted to dissociate himself. Regarding himself as a pioneer in 'scientific' physiognomy, Lavater formulated a scientific methodology of one hundred physiognomic rules, which could be studied to improve existing abilities and to acquire new interpretive skills. An abundance of illustrations linking specific body shape with particular moral trait helped in the (re)learning process (Graham, 1979; Finkelstein, 1991).

Lavater's physiognomy was extremely influential, widely disseminated with its merits being vigorously debated in a variety of scientific journals. According to John Graham (1979), the work was reprinted, abridged, summarized, pirated, parodied, and reviewed so often that it is difficult to imagine how a literate person of the time could have failed to have had some general knowledge of physiognomy. Fifty-five editions were published in the first forty years,
including sixteen German, fifteen French, two American, one Dutch, one Italian, and twenty English versions. Regular production of the work did not much slacken off until 1870, and the two Swiss editions in the 1940's swelled the total to 156 publications in all languages (Graham, 1979:62). Finkelstein describes how it was even turned into a type of parlour game with its laws been widely disseminated on cards, similar to playing cards, with an embossed head sectioned off into physiognomically visible attributes. Having a set of cards became fashionable amongst Europe's upper classes of the late eighteenth and early nineteenth century where, in spite of Lavater's presentation of physiognomy as a system of scientific character analysis, it became a form of entertainment. Graham also notes a sharp rise in the use of physiognomy and pathognomy by novelists in the late eighteenth century as a means of presenting character, and of revealing the truth about people. This, more than anything, probably accounts for the enduring nature of the ideas contained within physiognomy.

An important aspect of Fragments is Lavater's defence of physiognomy. The formulation of a scientific methodology was crucial in his defence as was establishing the 'science's' boundaries. He did this by distinguishing physiognomy from pathognomy:

Physiognomy ... is the knowledge of the signs of the powers and inclinations of men. Pathognomy is the knowledge of the signs of the passions. Physiognomy ... teaches the knowledge of character at rest; and pathognomy of character in motion. Physiognomy ... shows what man is in general; the latter [pathognomy] in what he becomes at particular moments; or, the one what he might be, the other what he is. (Lavater cited in Graham, 1979:49)

Moreover, Lavater also had to deal with detractors who argued that no system existed within physiognomics for distinguishing between feigned and real appearances. A countenance could be dressed in virtue, a posture of compliance may well be adopted, beauty could blind; in any of these scenarios the character analysis would be mistaken. While Lavater accepted that immediate dissimulation was possible under certain circumstances, he maintained that in the long run it would be impossible to sustain. Certain physiological features could not be changed, for instance, the shape of the head, eye colour, or general skeletal frame. Thus, the body could not lie; it would eventually uncover imposers. Furthermore, the conscious shaping of one's physical appearances over a long period of time would not result in a changed moral character. For Lavater, a person's character was locked into his or her physiological make-up from birth; changing the latter could not change the former and vice versa. Of course, misjudgments in character would occur when untrained eyes engaged in
physiognomy bringing disrepute on the science, but, for the trained eye, the body remained the place of truth.

In the final volume of *Fragments*, Lavater continued his efforts to have physiognomy cloaked in the mantle of science by developing Le Brun’s geometric theories to demonstrate a continual line between animality and humanity. In Lavater’s schema, the humanization of animal forms was accompanied by the line of facial angle between the eye and the chin gradually moving through the perpendicular to perfection at about ninety-five degrees. Twenty-four stages were identified by Lavater in his line of animality, which Magli describes as 'a slow metamorphosis that evolves according to a continuous process of gradual humanization' (Magli, 1989:122).

The resulting fantastic, ‘in between’ monsters, neither human nor animal, would have seemed credible at the time given the reported sightings of ‘monstrous tribes’ and ‘human marvels’ by explorers in strange and distant lands. The origins and extent of these beliefs will be examined later in the discussion on teratology. Lavater’s explorations in the ‘line of animality’ also had important implications for contemporary understanding of spirituality: because the appropriate body is chosen by the soul and because animals and humans are different manifestations of the one corporality, then the soul which is an animal must have completely forgotten its spiritual origins (Magli, 1989). Not only character, but now spirituality, potentiality for grace, proximity to God, etcetera, etcetera, are visible to the trained eye.

Undoubtedly the enthusiasm with which Lavater’s system was adopted by novelists and the wide debate it sparked in the scientific community, accounts for the way in which many of his precepts have become part of our cultural baggage. Even today, when cosmetic surgery demonstrates the fallacy of the precepts which are its raison d’etre, we find ourselves still construing character from outer body appearances. For example, the face, according to Lavater, spoke most eloquently of character. Shallow, parallel wrinkles on the forehead suggested a high degree of intelligence, rationality and wisdom (rule sixteen), whereas deep wrinkles signified stupidity and a weakness of mind (rule eighteen). Similarly, the eyes, the nose and the jaw were telling features. We are all familiar with the notions that certain eyes indicate a shiftiness of character, an upturned nose cuteness and/or obstinacy, while the chin is still taken as a measure of moral strength. Two centuries on, Lavater’s physiognomic system persists.
It would be wrong to assume that 'scientific' notions of physiognomy have descended to us in an uninterrupted line from Lavater. In three important works his ideas were taken as the starting points, fine tuned and re-presented so that character and corporality correlate with increasing precision and exactitude in each succeeding publication. In Cruise's *Phrenology Made Easy* (1874), forty unique character traits were linked to forty identifiable and specific physical formations of the face. For example, generosity was indicated by the closeness of the lips at the corners, selfishness by smooth lips, level of self-esteem by the stiffness of the upper lip, and purity by the closeness of the lips to each other. Notwithstanding this precise linkage of emotion and facial detail, Cruise cautioned the physiognomist to be aware of the effect externals such as ill health and accidents might have on appearances. Education, the training of the intellect, could also influence the formation of an individual's disposition (Finkelstein, 1991).

Writing two years later, Samuel Wells added emotional and spiritual experiences to the list of life-events which determined and shaped physical appearances. In his *New Physiognomy, or, Signs of Character, as manifested through Temperament and External Forms, and especially in the Human Face Divine* (1876), Wells argued for a radical inversion of the Lavaterian precept that the shaping of physical appearances would not produce the desired character changes. For Wells, it was possible to wilfully control and/or change outer form by affecting certain personality traits: 'we may direct and control even our thoughts, our feelings, and our acts, and thus, to some extent ...become what we will' (cited in Finkelstein, 1991:30). He also believed that desires and experiences were enfleshed and so changed corporeal form. Hence, inner goodness manifests as outer physical beauty, religious life can improve the face while indulgence and excess ruin outer appearances. The body becomes in Wells' physiognomy an open text from which the trained eye can not only read one's character, desires, and passions, but also one's entire life history:

... our bodies, our brains, and our features readily adapt themselves and clearly indicate the lives we lead and the characters we form. (ibid.)

While the face had always been the most revealing of all bodily sites in physiognomics, the overall shape of the body was also an important signifier of character. Wells paid particular attention to body shape as well as emphasizing the texture of the skin, the quality of hair, the size and thickness of the hands and feet, the fingernails and the degree of functional activity: all these parts of the body required interpretation if a full and subtle reading of character was to be obtained.
Other nineteenth century works on physiognomy include Theodor Piderit's *Mimic and Physiognomy* (1858), Louis Gratiolet's *Physiognomy and Expressive Movements* (1865), and Darwin's *Expression of the Emotions in Men and Animals* (1872). According to Kerns (1975), Darwin added respectability to this area of investigation and by the close of the century there was an abundance of work that related body types to moral and intellectual capacities. Of these, Cesare Lombroso's school of criminal anthropology spearheaded one of the most influential late-nineteenth-century social movements (Gould, 1977). Lombroso married the evolutionary theories of Darwin with the precepts of physiognomy. Using Darwin’s notion of atavism (human reversion to a savage state), Lombroso ‘discovered’ the atavistic criminal: criminals and deviants were regarded as throwbacks to our apish past. As such, Lombroso theorized criminals would have a distinctive morphology; he found the physical stigmata he was looking for when measuring both living and dead prisoners. Using many of the precepts of physiognomy, Lombroso developed a system whereby potential criminals could be identified from their morphology early in life, kept under surveillance and exiled from society as soon as their criminal nature was manifested in their behaviour. Typically, the criminal had a thick skull, an asymmetrical cranium, a low and narrow forehead, large handle-shaped ears, a jutting jaw, copious hair on the male chest, relatively long arms, prehensile feet with mobile big toes, and diminished sensitivity to pain as evidenced by their proclivity for tattoos. In comparing criminals to a control group of soldiers, Lombroso found significant differences in the incidence of such stigmata (Taylor, Walton and Young, 1973). While Lombroso’s theories met with criticism from the scientific community, his taxonomy of physical stigmata found much favour with authorities concerned with the containment of ideals and behaviour inimical to social order7 (see Gould, 1977:222-8). Today the criminal avatar survives; on the screen the stand over thug typically looks and acts like a gorilla - large, slow - thinking, brutal.

Phrenology was another offshoot of physiognomy which gained some popularity in the nineteenth century. Phrenologists maintained that mental faculties were located in distinct regions of the brain and that the size of the brain or cerebral organs was an index of their power of functioning. Further, since the contours of the cerebral cortex gave form to the skull, an analysis of an individual’s talents and character could be made by observing the

7 See also Michel Foucault (1979; 1980) in his histories of the prison and the hospital, where the importance of surveillance and the scientific classification of the body is stressed as the means of imposing a repressive social order in the modern era.
exterior of the head. Thus, the bumps and grooves that the brain impressed on the skull were taken as representations of an individual's nature, character and soul (Shapin, 1979).

Lavater's ideas surfaced again in the twentieth century with Spon (1934), who argued that character is disclosed by an examination of an individual's shape, colour, or outward appearance. While the face was important, much was revealed by other parts of the body such as hair colour and skin texture. But he went further by characterizing fat, big-boned individuals as lazy, short statured individuals as suspicious of others, and dark skinned people as selfish and revengeful. It is interesting to note that as soon as the focus shifts from face to body, the social and political interests of the day become apparent. The influence of social Darwinism and the political interests of imperial Britain are apparent in Spon's characterizations.

As with Wells and Cruse, Spon did not reject the notion that an individual's idiosyncratic experiences could be transposed into features of physical appearance. Prior to Cruse, the fundamental premise of physiognomics was that the relationship between body and character was fixed and immutable; now it seems that an individual could deliberately chose to look and act in a particular way and, by so doing, shape his or her identity. Spon, however, neatly circumvented this contradiction by presenting both physical appearances and social conduct as particular to the individual. Thus, in his physiognomy, the natural and social significance of, for example, facial wrinkles, is found: not only do wrinkles indicate intellectual activity and good character but also a life of dissipation if found under the eyes, especially in the young (Finkelstein, 1991:36-7).

**From the transcendant to the immanent: character to personality**

By the last third of the nineteenth century character had, in a sense, become transitory as it was accepted by physiognomists that somehow character was as interchangeable as the ways in which an individual chose to fashion his or her body. This fundamental change in physiognomics parallels the changes in the way people and things were understood during the eighteenth and nineteenth centuries. In *The Fall of Public Man*, Richard Sennett argues that the reformulation of secularism - the way things and people are made understandable in the world⁸ - and the shift from a concern with character to a focus on personality, marks a crucial break in the way the relationship between body and self is understood in this period.

⁸ In Sennett's words: 'secularity is the conviction before we die of why things are as they are, a conviction which will cease to matter of itself once we are dead.' (Sennett, 1976:21)
During the eighteenth century the secular was transcendental; things and people were understood by assigning them a place in the order of Nature. This belief was reflected in social organization where, for example, in both England and France, sumptuary laws assigned to each station in the social hierarchy a set of ‘appropriate’ clothes, and forbade people from any one station wearing the clothes of people in another rank. Since character was regarded as fixed at birth, the clothes one wore were not regarded as a reflection of the inner-self but rather as a sign of social status. In the nineteenth century, a secularism based on the code of the immanent arose to overturn that based on the transcendent. Feelings, sensations, facts, were now understood in their immediacy rather than by fitting them into a pre-existing scheme. The immanent, the instant, the fact, was now taken as a reality in and of itself (Sennett, 1977:20, 65-72).

This indicates a shift from a belief in ‘Nature and Nature’s god’ to one centred on the immediate life of humans, and their experiences as a definition for all that can be believed in (ibid.:151). In this scheme of immanent belief, personality, the immediate impressions of the self-in-the-making, replaces character, a cosmic preordained given, as a means of understanding the self. Sennett points out how, in the absence of a deity, phenomena came to seem real in and of themselves as immediate experience. Any appearance a person made now had to be taken seriously for it was in some way real, because it was tangible, and it might provide clues to the inner-self of the stranger. An individual’s dress and deportment, thus, came to be taken more and more as an expression of his or her personality or inner self. Further, it was believed that ‘one is what one appears [and] when one’s own appearances change, there is a change in the self’ (ibid.:152). Like courtiers in the court society, one now had to take pains to manage the impressions one might give off in the public life of strangers. Personality, unlike natural character, is able to be fashioned, it is a project under the control of one’s self-consciousness. In keeping with these precepts, a greater bodily self-consciousness and self-scrutiny emerged in public life.

It would be a mistake to think that the reformulation of secularism happened of its own accord; it had a material basis. The shift from the transcendental to the immanent was an outcome of the impact industrial capitalism was having on the material life of the public realm. Luxury items, once the province of a wealthy elite, were now being mass produced and becoming increasingly cheaper. In the process of their gradual percolation downwards through all sectors of the population, it became obvious that differences in status were social rather than natural. This was underlined by the mass-production of clothes from mass-
produced patterns which resulted in everyone dressing in a similar fashion (ibid.:20). Clothes ceased to indicate status; they now expressed personality. People fashioned themselves rather than being created; instead of being fixed immutably in the divine Natural order, individuals could now make a place for themselves in the new industrial (social) order.

Given the reformulation of secularism, the attempts by Cruse, Wells and Spon to incorporate the beliefs of the time into physiognomy are understandable. If personality is understood in terms of immediate impressions which are subject to self-conscious manipulation, why not make the shaping of physical appearances also subject to self-conscious direction? The fundamental error of this reasoning is that personality is confused with natural character; both are treated as the same thing when categorically they are different. Natural character is beyond the control of an individual; character is of the cosmos while personality is of this life. Personality is the self-in-the-making and is reflected in the way one clothes the body while character, in the physiognomic sense, gives physical shape to the body.

As a consequence of this about-turn in fundamentals, the pseudo-scientific character of physiognomy was now transparent and any pretensions to scientific status were totally discredited and abandoned. But this did not mean the end of physiognomic principles, rather it signalled a change in form and presentation so that their penetration of social consciousness is now more pervasive and, arguably, more influential than at any other point in western history. In contemporary society, the idea that character, or, rather, personality, is immanent in appearances, that outer appearances indicate inner self, is not even subject to scientific scrutiny; it has become a truism, a self-evident fact embedded in the consumer culture of late capitalism. To understand the 'how' of this intensification of bodily consciousness we need to examine the social context in which it emerged, that is, the events of the opening decades of the twentieth century.

CONSUMERISM: THE IMPACT ON BODY MEANING AND BODY CONSCIOUSNESS

Consumer culture is characterized by a distinct way of life geared around the accumulation and consumption of an ever-growing range of goods and experiences (Featherstone, 1983). It has its origins in the Industrial Revolution with the preconditions for mass consumption as a distinctive way of life in place by the second half of the nineteenth century. Mass production had increased the amount of goods available, new technologies - fashion plates,
daguerreotypes, tintypes, and rotogravures - reproduced a plethora of images advertising the goods available, and, a new innovation in selling and buying, the department store, encouraged customers to browse amongst displays of goods which conjured up images of luxury and the 'new' (Chaney, 1983). Consumerism, however, remained the province of the wealthy upper and middle classes until the early decades of this century when the introduction of assembly line techniques greatly increased productive capacity, releasing a plenitude of consumer durables (cheap manufactured clothes, household goods etc) onto the market. By the 1920s, improvements in real wages, a decrease in working hours, and the introduction of instalment buying had not only stimulated demand, but also established the conditions for the incorporation of workers into consumer culture (Ewen, 1976). However, the puritan ideology of hard work, thrift, and sobriety which had persuaded the working class to participate in capitalist production, now acted as a brake to their adoption of a consumerist lifestyle involving new needs and desires. Puritan mores collapsed, however, under the assault of the Great War 1914-18 and the impact of media advertising which began during the inter-war years. Attitudes to the body, sexuality, leisure, and lifestyle were changed irrevocably.

In his book *Anatomy and Destiny: A Cultural History of the Human Body*, Steven Kerns (1975:191-207), argues that the war triggered a reevaluation of class and gender relations, sexual morality and the ways in which people experienced their bodies. Having fought a war alongside the aristocracy, subjected to their bumbling incompetence, workers were no longer prepared to be subservient to aristocratic ideology on civvy street. Traditional gender relations were fundamentally changed forever as women moved from the home into the war-effort, performing in heavy industry as effectively as their male counterparts. Women took the opportunity to look after their own sexual needs while their men in the trenches did without, or made do with masturbation, prostitution, or homosexuality. The elaborate decorum which had ruled Europeans since the Victorian era was abandoned as the ways in which people dressed, understood, enjoyed, and cared for their bodies were radically transformed by the events of the war. The way men experienced their bodies was further affected by, 'the filth, the disease, the brutality, the pain and the killing' that accompanied trench warfare (ibid.:255).

It is not surprising then, that during the inter-war years the celebration of the leisure lifestyle and its new norms and standards of behaviour by the new media of motion pictures, tabloid press, mass circulation magazines and the radio, fell on receptive ears. Stuart Ewen (1976),
outlines the impulse for twentieth century advertising in *Captains of Consciousness*. At the turn of the century capitalism was beset with a twin crisis of production and consumption. On the one hand workers were disillusioned with capitalism and union resistance to the increasing tendency to reduce workers to 'mere appendages of machines' was growing. On the other, the worker's attitudes, mores, instincts, set them against the hedonism implicit in consumerism. Production was revolutionized in 1910 with Henry Ford introducing the 'line production system': more could be produced in less time. While assembly line techniques reduced workers to ever smaller cogs in a larger machine increasing the potential for worker discontent, shorter hours and higher wages helped defuse the situation to some extent. Not content with this, leading industrialist shifted the struggle from the material to the ideological by deploying 'social managers' (that is, advertisers) to shift the focus of worker discontent from the relations of production to themselves (Ewen, 1976).

Advertisers did this by creating desires, habits, and personal needs which could be met by the goods of production and which fluctuated dependently with the expanding marketplace. Floyd Henry's social psychological theories on how people developed a sense of self, underpinned much of the advertising of the 20s: 'our consciousness of ourselves is largely a reflection of the consciousness which others have of us....My idea of myself is rather my idea of my neighbor's view of me' (ibid.:34). In this way the notion which had emerged in Victorian England of the individual as the object of continual and harsh scrutiny was disseminated throughout American society. Accordingly, consumers switched critical functions from the product and the production process to themselves and the processes of the body. It was no longer wage slavery which was the source of dissatisfaction, but one's bad breath, now elevated to the pseudo-medical condition, halitosis; other bodily odours needed to be disguised, held at bay with a variety of mass produced perfumes and colognes; the skin, appearances are renewed, revitalized, preserved by unguents obtainable on the market. Notions of success and failure were increasingly portrayed in terms of the use or non-use of mass-produced commodities which eclipsed the consumer's natural maladies of which s/he has been made self-consciously aware. In this manner, workers' discontent with the relations of production was channelled away from class action and into a nonviolent, apolitical, individualized solution: civilising the body with the fruits of mass production. The foundations for consumer culture were thus established in the United States during the 1920s and in Britain by the 1930s (Ewen, 1976:31-48).

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Ewen takes pains to point out that the masses were not easily duped through a process of mass deception. Rather, new products were embellished with scientific and pseudo-scientific justifications; consumerism and the freedom to consume was portrayed as a fundamental feature of democracy; the undermining of traditional values was taken as a reasonable critique of dogmatic authority and patriarchal domination. Couched in these terms, elements of the new value complex were welcomed as genuinely progressive (see also Kellner, 1983; Leiss, 1983). What is of particular relevance is the way in which the body is deployed within this culture both as a means for selling mass produced goods and as a site of consumption.

**Appearances and self in consumer culture**

In his analysis, *The Body in Consumer Culture*, Mike Featherstone (1983) shows how since the 1920s perceptions of the body have been dominated by a proliferation of visual images emanating from motion pictures, photographs, television, advertisements. All promote idealized images of the body and associated lifestyles. Advertising has been to the fore drawing upon the recurring themes of youth, beauty, energy, fitness, slenderness, movement, freedom, romance, exotica, luxury, enjoyment, fun, popularity. Whilst these images give a certain panache and credibility to the product, the secondary associations are that only certain types of bodies have panache, fun, are popular, enjoy life, and experience romance, luxury, and freedom, namely the young, slim, fit, active, and healthy. Under this highly ideological assault on the senses, the meaning of the body changed as advertisers created new desires and stimulated demand by discrediting traditional values of thrift, moderation, and abstinence. Notions of the body as a vessel of sin were replaced with images of the body beautiful that were openly sexual and associated with hedonism, leisure, and display. The body quickly became perceived as a vehicle of pleasure and self-expression. In this context, bodily appearances are all important. The closer it approximates the idealized images of youth, health, and beauty, the higher its exchange value in both personal relationships and in career advancement. That is why so many people today invest so much time, effort, and money in maintaining health and optimum functioning of the body for the purely instrumental goals of enhanced appearance and more marketable self (Featherstone, 1983).

In the 1930s, Helena Rubinstein created the new female ideal in her equation of youth equals beauty equals health. Slenderness was assumed. The ideals of slenderness, youth, beauty, and health were incorporated into the ideal image of the new man later in the century (see Liggett, 1989:177-8 on the 'new man'). More latterly, the ideals of sexuality, fitness, and vitality have been added to the positive attributions of the slim body. The corollary is to
ascribe negative sanctions to the fleshy, overweight, or obese body. Such bodies evince bodily neglect, laziness, low self-esteem, and even moral failure. The slim/beauty obsession, and its opposite, fat/ugly, has had tragic consequences for teenage girls, young women, and a growing number of young men, with the eating disorders anorexia nervosa and bulimia reaching epidemic proportions in these populations throughout the western world.

Idealized images invite comparison. Not surprisingly, growing numbers of men and women are devoting increasing amounts of time to 'body work' to counter signs of aging, bodily deterioration, and excess weight; a variety of technologies to renew and revitalise, to mould and re-shape the body are deployed to this end. A multi-billion dollar complex of beauty, cosmetic, fitness, health, and leisure industries has grown up around the provision of those technologies. The accompanying marketing strategy encourages potential consumers (and by now, who isn't one?) to adopt a critical attitude to body and self, to induce a sense of insecurity and anxiety over bodily appearances.

**Technologies of the Body**
The main players in the 'body maintenance' game are the US thirty-three billion dollar-a-year diet industry, the US twenty billion dollar cosmetics industry, the US 300 million dollar cosmetic surgery and the gymnasium/body building/health-fitness industry. Capitalizing on the commonsense assumption that being overweight is a health risk, when in fact it is not, these industries have successfully promoted themselves as the nexus where thinness, fitness, and health coalesce. Most successful in doing this has been the diet industry which has medicalized fat to the extent that many people are obsessed with what and how much they eat, while the only slightly overweight live in fear of hypertension or an impending heart attack. Not surprisingly, diet books have been some of the biggest best-sellers over the last forty years, fad diets regularly materialize, do the rounds and disappear, and, in a relatively

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10 Indeed, negative economic sanctions are placed on obesity, especially in the case of women where it amounts to a condemnation to low socio economic status (Wooley, Wooley & Dyrenforth, 1979).

11 Chernin (1981) cites Dr Andres' research on the relationship between longevity and weight which shows that people twenty-four to thirty-eight percent overweight, as defined by statistical charts, actually live longer.
new development, paid professional helpers provide moral support and tips to groups\textsuperscript{12} who have banded together to overcome the ugliness inducing and life threatening fat.

A plethora of centres have sprung up linking fitness with health (for example, The Clive Green Health Centre, Healthlands Fitness Centre) and which regard the body as plastic; as something to be moulded into the desired, idealized shape, endowing it with a healthy vitality in the process. 'Body-sculpting' is in. Specialists magazines urge body-builders to 'Create a masterpiece' and to 'Sculpt your body contours into a work of art. Men and women spend hours pumping iron, and fortunes on specialized diets, delighting in the solitary and narcissistic pursuit of sculpting the perfect body, and the self as mirrored in that body. Moreover, the thrill of being in total charge of the shape of one's own body substitutes for the lack of economic and political control experienced in an increasingly unmanageable culture (Bordo, 1985).

For those more interested in holding the ageing process at bay, the consumer's gym is a cornucopia of technological wizardry: the Astro Trimmer for waist and stomach reduction, the Sauna Belt, the Mark Eden Bust Developer - especially designed to allow women to develop their busts at the same time as slimming other, less desirable bulky parts, the Physiomex, Dyna Gym and the Mediaphore use electrical impulses to encourage the absorption of a special slimming substance called Cellulium into the tissues. To regain lost youth step into the Oxlender 2000 where one is sprayed with water, steam, oxygen, ozone, and herbal oils - all intended to rejuvenate tissues, accelerate metabolism, and generally tone down and slim the body (Liggett, 1989). Have a snack at the health food bar on the way out and don't forget to purchase your hi-protein compound for those health giving beverages you will need to maintain your vitality between visits. Utilize the fitness centre's technologies of the body for enhanced appearances and a rejuvenated self. A fit, trim, and vital body is a healthier, happier, more youthful, beautiful, and sexier self. However, body work in the gym will not produce the desired results for all people. Wrinkles remain, facial skin still sags, breasts remain the wrong shape or size, as do the various parts of the face, and cellulite refuses to budge; the cosmetic surgeon's scalpel is the only option.

\textsuperscript{12} More than thirty million people in twenty-four different countries have attended Weight Watchers meetings since 1963. Another group, Over-Eaters Anonymous was formed in the US in 1965 and by 1980, 1400 groups were operating where people could talk about their problems with their bodies. Weight Watchers provides the public forum for bodily self-surveillance, while 'Over-Eaters Anonymous' concretizes the connotations of shame, uncotrollability, moral failure, and medicalization, induced by obesity.
**Cosmetic surgery**

An intimidating list of operations are available: otoplasty (ear correction), blepharoplasty (eyelid reconstruction), rhytidectomy, meloplasty and cerviofacial meloplasty (tightening of skin over face or face lift), rhinoplasty (nose re-profiling), mammoplasty (breast augmentation or reduction), chemabrasion (peeling skin and wrinkles off face with acid), dermabrasion (freezing skin and sandpapering away facial wrinkles using a high-powered rotating wire brush), gastroplasty (stomach stapling in which stomach is sutured together), abdominoplasty (removing or sealing off areas of the intestine for weight loss). Other techniques include lipectomy or liposuction to suck away fat from most parts of the body, forehead and cheek implants of fat or bone transplanted from other areas of the body, the surgical creation of dimples in the cheeks or midpoint of the chin, jaw surgery, reshaping of the chin, often by silicone implants, and hip-shaving for that slimmer silhouette. Hair transplantations are recommended to cover the bald patches on the scar tissue along incision lines and tattooing can provide a voluptuous new lip line.

While names such as blepharoplasty, rhydectomy, rhinoplasty, and mammoplasty add a touch of surrealism, undoubtedly tapping subconscious desires to transcend the reality and limitations of corporeality, they also camouflage the very real pain and dangers associated with the operations. Chemabrasion is painful and relatively risky. It involves burning the skin off the face with an exfoliative such as phenol over a period of several hours. Naomi Wolf quotes cosmetic surgeon Dr. Thomas Rees on the face lift: 'Abrasion and peeling traumatizes [sic] the skin ...with either procedure, the skin can be removed too deeply and result in an open wound ...deaths [from cardiac arrest] have followed a chemical peel' (Wolf, 1990:256). Patients must stay under close medical supervision for several days, including bed rest for the first two days. Finkelstein on recovery from dermabrasion: 'A dressing over the face must be worn for ten days. During this period, the skin is raw and oozes a yellowish liquid; after about thirty-six hours a scab forms which reduces the oozing. As with chemabrasion, there is extensive swelling and the skin is extremely sun sensitive for several months' (Finkelstein, 1991:99).

The complications with mammoplasty are legion. In seventy percent of cases, breasts become rock hard as scar tissue hardens necessitating the removal of implants, or the surgeon breaking up the lumps using his bare hands. Implants leak silicon which then migrates throughout the body with unknown effect, immune-system problems and toxic shock syndrome are predicted in medical journals. The erotic response of the nipple can be
permanently killed off; weeks of recovery are required during which time the breasts must not
be touched. Despite the dangers and discomfort, the breast remains the most frequently
remodelled part of the anatomy with 436 operations being performed every day of the year
in the US compared with 183.5 facelifts (Wolf, 1990).

As if the suffering caused by eating disorders was not enough, cosmetic surgeons add to the
misery. Severe malnutrition, liver damage, liver failure, irregular heartbeat, brain and nerve
damage, stomach cancer, immune deficiency, pernicious anaemia, and a two to four percent
death rate within days of the operation are only some of the outcomes of gastroplasty or
intestinal stapling. In America, fourteen women have already died from liposuction, the
fastest growing procedure in the field (Wolf, 1990; see also Finkelstein, 1991:81-106; Liggett,

Notwithstanding the expense, associate dangers, pain, and loss of sensation, cosmetic
surgery is the growth area in the beauty industry. This signifies not only a change in attitude
towards the body but also a reaffirmation of the importance the social interpretation of
corporeal appearances and the meanings they (appearances and interpretations) have in the
constitution of a persona-cum-inner-self in consumer society.

Firstly, the embeddedness of physiognomic precepts in our culture. Aesthetic rhinoplasty,
the most common form of facial surgery, bears this out. Yesterday's physiognomists placed
particular emphasis on the nose as the most telling facial structure; over eighty types of
noses and an equal number of moral dispositions were identified (Magli, 1989:92). Today,
plastic surgeons promise that nose correction will make the individual more attractive and
youthful - a fined down nose imparts elegance; a tipped or shortened nose makes the face
more childlike, younger, and hence more successful socially (Finkelstein, 1991:96-7). The
impulse for changing the shape of the nose seems to come from deeply held physiognomic
beliefs, awakened and played upon by the purveyors of beauty, that social rewards will follow
if one conforms to a cultural ideal.

Secondly, in a secular world based on the code of the immanent, appearances are all
important: you are what you look like. Sennett's unfinished project, personality, the self-in-
the-making, has become the measure of the person rather than Natural character. Following
this logic, it was only a matter of time before a change of clothes was not enough to signify
a change in personality; changing the shape, the appearances of the body is the new
requirement. Advances in technology and surgical skills made the re-formation of the body possible. Unlike the physiognomists of old, who held that dissimulation could not change character, their counterparts today, the cosmetic surgeons who assign personality traits to idealized forms of the body, promise that a change in body shape will bring about a 'new' you. Consequently, many clients have unrealistic expectations about what surgery will do for them; marriages will be saved, careers boosted, a complete transformation of and improvement in personality are some of the fantasies. As if to confirm the old physiognomic precepts, psychiatrists report a growing list of disappointed clients who had expected cosmetic surgery to cure their neuroses and solve all life's problems. However, what is of real interest is the changing meaning and attitude towards the body. In an inversion of the Aristotelian configuration, the corporeal is reshaped to give a new soul. Today the principles of physiognomy are very much alive, inciting consumers to carve and reshape their bodies, as if they were blocks of plastic, according to the dictates of fashion.

Thirdly, and tragically, after cosmetic surgery the body, in a sense, becomes plastic. Wolf (1990), reports the loss of sensation after breast surgery, damage to facial nerves resulting in numbness or reduced sensation as a side effect of the face lift, the loss of the sense of smell is a possible outcome of a nose job. Having lost sensation, these bodily parts lose their integrity. They lack continuity with the rest of the body. They are artifact. Plastic.

Finally, cosmetic surgery marks the fetishization and commodification of the body in consumer culture. Various parts have been separated from the body, idealized and used to sell mass produced goods. These idealizations have, in turn, become commodities to be bought and sold in the market. Take actress Cher for example. She has spent over twenty-four thousand pounds having her nose slimmed down and shortened, her cheek-bones shaped up, her chin modified by silicone transplant, her tummy tightened, thighs reduced, bottom curvaceously reshaped, navel made more petite and 'girlish', and no less than three breast lifts (Liggett, 1989:28). Cher's approach to her body is an exemplar of the body as commodity attitude: 'When there is a bit of me I don't like, I change it' (ibid.:128). While the purchase of idealized body parts for cosmetic purposes involves a reshaping of the individual's own body, the same attitude operates in the growing trade in spare organs (for example, kidneys) from the third world for first world consumption. Both are facets of the same process: the commodification of the body. Under the cosmetic surgeon's scalpel the meaning of the body changes, where, along with character and appearances, the body is only skin deep: everything that is solid melts into air.

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Body language

Having utilized the various technologies of the body and achieved the desired outer appearance does not signal the end of body-technique in the cultivation of others. Not only must cosmetic appearances create the right aura of youth, health, vitality, and competence, but individuals must continually monitor the body so that the right messages are transmitted. Kinesics, the study of the grammar of body language, claims to show exactly what individuals are thinking or feeling through the interpretation of facial expressions, body posture, and gestures. Kinesics has been a big hit in the sales and self-help literature: 'keep a controlling hand in arguments and negotiations', 'how to tell when the other person is lying', 'project unspoken orders that must be obeyed' (Featherstone, 1983:29). Originally, courtiers were the only ones whose status was affected by deportment; today everybody is to some degree. Personnel officers are trained in kinesics, the latest sub-branch of physiognomy, to read the truth from the interviewee's posture; it facilitates sociation by providing the means to control one's non-verbal, bodily communications while deciphering those of others. This, of course, presupposes complete and absolute control over the body and its movements, that is, 'able-bodiness', non-disablement.

SUMMARY AND CONCLUSIONS

Aristotle's belief that the soul gives 'form' to a mass of shapeless 'matter', the body, and, from this presupposition, that the inner self can be known from outer appearances, remains remarkably intact five thousand years on. From the sixteenth to early in the twentieth century these assumptions underpinned the pseudo-science of physiognomy. In the sixteenth century della Porta's physiognomy derived character from the animal one physically approximated; a century later Lavater abandoned this approach and his formulation of one hundred physiognomic rules added precision and method to the 'science'; towards the close of the nineteenth century physiognomists claimed the added ability to read an individual's idiosyncratic experiences from his or her body; in the twentieth century we are far too sophisticated to use either the crude analogies of della Porta or the pseudo-science of Lavater. Rather, the basic tenet of physiognomy, that the body is the window of the soul, has become a truism of consumer culture. Under a welter of images the new benchmark is the idealized 'body beautiful' in which the desired characteristics of youth, health, vitality, freedom, popularity, sexuality are held to be immanent. The personality which these traits constitute differs from the notion of natural character insofar as it is cultivated in large part
by sculpting the body to conform with the ideal which mirrors the desired self or personality. This is possible in consumer culture where the body is regarded as plastic; with body work or, cosmetic surgery, the body can be made to conform to the cultural ideal.

In the day-to-day life of contemporary society, the precepts of physiognomy dominate with judgements about the moral disposition of character increasingly being made on the basis of outer appearances. Physiognomy is part of the logic of a culture saturated with visual images that convey messages of worth, need, and desirability. It stands to reason that life chances are more than ever dependent upon aesthetic aspects of the body and the degree to which outer appearances conform to cultural ideals.

What one does with the body has always been as important as appearances. An etiquette of deportment, gesture, elegance of movement, coalesces in a grammar of the body which must compliment appearances. It completes the picture, ensures the right impression is created. Movement, or rather the ability to control bodily movement, and performance has become ineluctably associated with character, personality, the inner self. In the next chapter performance and movement, the physiological functioning of the body, are examined in this exploration of the relationship between body, self, and society.
In Chapter II, it was shown how throughout history the body has been regarded as a surface upon which character is inscribed, an open book from which the 'truth' of the person could be read. Dress, deportment, elegance of movement, and civility provided extra clues; the control and deployment of the body give a closer reading. With the valorization of appearances and behaviour during the seventeenth century, status and position in court society were very much tied to bodily decorum; today life chances are enhanced and more readily attainable the closer one's appearances approximate the idealized images which saturate the media. At all points the underlying physiology must be free of pathology; it must be whole, upright, fit, and mobile. What then of the body which violates these ideals?; how has it been categorized, explained and responded to throughout history?; what of the souls of these bodies?; have particular subjectivities been socially imposed upon these bodies? These questions will be reflected in the next two chapters as the genealogy of the disabled subject is traced via a consideration of the anomalous body. This chapter will reflect on monsters and freaks as the objects of scientific and commercial practice up to the twentieth century. The following chapter will focus on the roles of the eugenics movement, the Plunket Society, the medical profession, and the voluntary agencies dedicated to helping 'cripples' in shaping the dominant perception of the anomalous body, the creation of disability, and the disabled subject in New Zealand.

TERATOLOGY: THE SCIENCE OF MONSTERS

Visual records of the anomalous body extend to us from the rock drawings of a giant double-headed, male figure, with four fingers on the left hand and six on the right, made by Australian Aborigines in pre-history (Warkany, 1959:84), and the Egyptian wall paintings of 5,000 years ago depicting people with clubfoot and achondroplasia (Barrow, 1971:119). Barrow also cites texts which argue for the possibility that many of the mythological monsters and gods may have arisen from observations of malformed infants. From this perspective, the Greek god Polyphemus was a cyclopic monster, Siren, a sympodial foetus, Janus, a diprosopus one, and the Egyptian god Ptah, an achondroplastic dwarf.
What then are monsters? The earliest written records are found on ancient Babylonian clay tablets which are thought to date back to 2,000 B.C. The Babylonians, the founders of the science of astrology, believed that anomalous births indicated the star's positions, and were, hence, portents of the future. Two of the tablets contained a list of sixty-two human malformations¹ and their corresponding prophetic meanings as divined by the Chaldean priests. This belief continued into the Greek and Roman civilizations. The Latin word *monstrum*, from *monstrare* (to show) or *monere* (to warn) is derived from this concept of a monster's property of foretelling the future (ibid.:119). Some monsters were interpreted as signifying good fortune, others as the harbingers of calamity. Selective infanticide was, thus, practised in Greece and Rome as a means of preventing disasters predicated on malformed births. In Rome hermaphrodites were always executed at birth, but when danger threatened or a catastrophe occurred other monstrous children were rounded up and sacrificed (Warkany, 1959:86).

Opposing the belief that monstrous births were supernaturally inspired and portentous, is a history of thought and empirical investigation which sought to provide rational explanations for anomalous births. Teratology², the science of animal or vegetable monstrosities, has descended to us from the classical Greeks, notably Aristotle, Ambroise Pare, Etienne and Isidore Geoffroy Saint-Hilaire - the Parisian father and son team who coined the term and established teratology proper in 1832 - and Dr. Josef Warkany, the author of the standard medical textbook *Congenital Malformations* (1971). (Fiedler 1978; see also Howard 1977; Barrow 1971)

In *On the Generation of Animals*, Aristotle examined a number of the current etiological theories of his time some of which he accepted, others he rejected. However, scholars in the Middle Ages and the Renaissance were to uncritically embrace all the theories Aristotle had considered. These were published in a number of books from the mid-sixteenth to mid-seventeenth centuries which were, in Barrow's words, 'descriptive texts filled with absurdities but splashed through with sound observations' (Barrow, 1971:119). Among them was Reuff's (1554) *De concepts et generation homines*; Lycosthenes's (1557) *Prodigiorum ac ostentorum chronicon*; Ambrosinus's (1642) *Ulysis Aldovandi's Monstoroum historia*; and Ambroise

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¹ Remarkably, only one of these malformation can be regarded as impossible or mythical. Most of the remaining sixty-one malformations are listed in modern publications on congenital anomalies (Warkany 1959, p.86).

² Derived from the term terata which indicates monstrous formations at birth.
Pare's (1573) *Monstres et prodiges* (Monsters and Marvels - hereafter *Monstres*). Pare, a French Renaissance surgeon, is credited with having written the book on monsters; a book which achieves a synthesis of philosophy, astronomy, philology, morality, medicine, and surgery. Pare's interest in monsters evolved out of his work on human reproduction and his search for causal explanations as to why anomalous forms occurred. Unlike the authors of many of the other Renaissance treatises on monsters, Pare was not concerned with their meaning but with their existence. From the outset then, Pare's consideration of monsters was a matter of 'scientific' inquiry based on the empirical observation of the many specimens he collected over a number of decades.

*Monstres* begins with Pare distinguishing between Monsters, Marvels, and Maimed persons. Monsters fall completely outside the course of nature, such as a child born with two heads or with extra or missing limbs. Marvels go completely against nature as in a woman birthing a snake or a dog. Maimed persons go against nature in their physical malformations, for example, the blind, hunchbacks, hermaphrodites, extra or fused toes or fingers, and so on. The third category, Maimed persons ('physically disabled people' in today's parlance), seems to be an afterthought, a residual category in which Pare slots those who, while remaining within Nature, transgress and degrade it. A view later championed by the eugenists of the late nineteenth and early twentieth centuries who argued that people with congenital disabilities 'lowered' or polluted the human stock of a nation.

Drawing upon his contemporary Boistuau, and others including Aristotle, Pliny, Saint Augustine, and Saint Paul, Pare completes the first chapter with the section 'On The Causes Of Monsters':

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3 Of the thirty human monstrosities illustrated in *Monstres et prodiges*, twenty-six have been "scientifically" identified (see Pallister, Jackson & Delaunay in Pare 1982:177-80). The remaining four constitute fantastic human/animal hybrids.

4 That Pare omits Giants and Dwarfs from his text probably reflects the contemporary view that their condition was considered an act of God. Commenting on this, Fiedler (1978, p.47), notes that Casper Schott (1662) classifies Giants and Dwarfs as *mirabilia hominum*, human marvels, as opposed to *mirabilia monstrorum*, monstrous marvels. Until the Saint-Hilaire's founded teratology proper in the nineteenth century, anomalies of scale were treated differently from identity, sex, or human/animal anomalies. It seems that the way Pare uses the words *monstres* and *prodiges* is not quite synonymous either with what the sideshow calls 'human oddities' or the medical researcher 'congenital malformations' (ibid.:234)
The first is the glory of God. The second, his wrath. The third, too great a quantity of seed. The fourth, too little a quantity. The fifth, the imagination. The sixth, the narrowness or smallness of the womb. The seventh, the indecent posture of the mother, as when being pregnant, she has sat too long with her legs crossed, or pressed against her womb. The eighth, through a fall, or blows struck against the womb of the mother, being with child. The ninth, through heredity or accidental illnesses. The tenth, through rotten or corrupt seed. The eleventh, through mixture or mingling of seed. The twelfth, through the artifice of wicked spital beggars. The thirteenth, through Demons and Devils. (Pare, 1982:3-4)

Pare illustrates each cause with an example. Thus, Siamese twins or an autosite parasite represent too great a quantity of seed (ibid.:8-23) while an armless man and headless female represent a lack (ibid.:33-8); a frog faced girl and a furry girl are the result of imagination (ibid.:38-42), and when equal amounts of male and female seed are contributed neither predominates and hermaphrodites result (ibid.:26-31); a man-swine and a man-goat hybrid (ibid.:67-73) are salutary warnings to lonely peasants who might be tempted to mingle their seed with the beasts they muster.

With his list, Pare set the parameters of the debate on the etiology of monsters. A perusal of the histories of teratology (especially Warkany 1959, 1971, 1977; Barrow 1971, also Fiedler 1978, who draws heavily on Warkany), shows that Pare's etiology survives today: sometimes as stated by him, sometimes cloaked in the jargon of modern clinical and experimental teratology. For example, belief in supernatural causality is still found today among some Christians who interpret human malformations as 'God's will'; while the rotting or corruption of 'seed' is not thought applicable to the male seed today, it is believed that the female seed 'corrupts' as she gets older, increasing the probability of monstrous births; it wasn't until the nineteenth century that cause six, an abnormally shaped womb, was superseded by Saint-Hilaire's proposal that amniotic bands produced most malformations. Benirschke (1977:81), confirms this belief arguing that the amputation of limbs and facial anomalies are caused by amniotic bands. 'Imagination' (commonly 'maternal impressions'), Pare's fifth cause, dates back to the story of Jacob (Bible: Genesis, 30) who got Laban's sheep to look at stripped poplar and hazel trees when pregnant and thereby produce spotted and streaked progeny (Barrow, 1971:121), was widely held as a valid cause of malformations until the 1920s. However, recently it reappeared as 'psychological shock' or 'emotional stress' which some scientists believe can affect fetal development and, thereby, produce malformations. Similarly, Pare's ninth cause, 'hereditary and accidental illnesses', was rejected by nineteenth century science but since the discovery by modern researchers that
DNA (deoxyribonucleic acid) carries 'encoded' genetic information in the cell nucleus, and is responsible for eighty-five percent of all malformations. It seems that the ancient theory of the 'germ originally monstrous' has carried the day.

According to Warkany (1959:90), the belief that different species could interbreed and produce hybrid monsters (Pare, cause eleven) probably originated in India and Egypt where it was taught that the soul could transmigrate from human to animal, and that animals were equal or superior to humans. A monstrous infant that resembled a particular animal was, therefore, not deemed repulsive but accorded the honour due that animal in the official religion. Also, since the cohabitation which produced such sacred monsters was regarded as unnatural but not sinful, it did not lead to the persecution of the mother (ibid.). But in countries where Mosaic and Christian law prevailed, such births were viewed as a serious abomination of God's law, and all implicated were punished accordingly. Thus, in 1642, a man in New Haven, America (Fiedler, 1978:246) and a girl in Denmark 1683 (Warkany, 1971:15), were executed for supposedly cohabitating with animals and producing hybrid monsters. The 'hybrid theory' also points towards the origins of contemporary expressions, such as harelip, which are used to describe certain malformations.

At the time Pare was writing, it was widely believed that demons, sorcerers, witches, incubi, and succubae\(^5\) were lurking everywhere, waiting to torment humans, sleeping or awake\(^6\). The issue of any of these associations would inherit the imagined features of the devil\(^7\). Thus, monstrosities, such as club feet, shortening of the upper extremities, long and deformed ears, hairy nevi, and syndactylism\(^8\) could have been interpreted as signs of satanic origin (ibid.: 16), and, along with their mothers, put to death. However, Pare the humanist unequivocally rejected the possibility of cohabitation with Devils (Pare, 1982:93). Using his knowledge as a physician, he asserted that it was indigestion that induces a person to writhe, stammer, and

\(^5\) Incubi and succubae are respectively male and female demons who descend on sleeping persons and have sexual intercourse.

\(^6\) This was especially true of fifteenth and sixteenth century Europe which was embroiled in a Church inspired witch hunt, complete with a theology of demonology and the widespread persecution of, mainly, illiterate peasant women (Anderson & Zinsser, 1988:161-73).

\(^7\) The film Rosemary's baby, is a modern representation of the belief that incubi (in this case, Satan) can have intercourse with a sleeping female and produce offspring that inherit the devil's features.

\(^8\) Hairy nevi indicates extended pigmented areas of the skin covered with hair; syndactylism is the lack of differentiation between two or more digits.
groan in his or her sleep and not, as widely believed, sexual activity with an invisible succuba or incubus (ibid.:105). This contrasts markedly with his ability to present allegorical figures, miraculous creatures, and hybrid monsters (ibid.:67-73) as scientific fact, as material reality.

However, the importance of the Renaissance texts was to provide an etiology of monsters which combined both mythological and natural explanations. More importantly, these works created a standard teratology in which monsters, myths, and superstitions were given life. Sometimes written in Latin, sometimes in the vulgar tongue, their readership was not confined to scholars. And once monsters became the subject of a scholarly discourse that was open to all and sundry, their existence was legitimated: monsters became real. Even more so, given that in these authoritative texts, the accompanying illustrations reproduced infant terata and aborted, malformed fetuses as full adults capable of independent life in all their monstrosity.

From monsters to malformations

Earlier, the scientization of the 'unscientific' physiognomies of Aristotle and della Porta, by Turner (1641), Le Brun (1698), and, especially, Lavater (1775-78) who formulated a scientific methodology of one hundred physiognomic rules, was noted. In a parallel development, elements of the pseudoscientific etiology developed by the Renaissance teratologists were superseded with theories derived from the developing sciences of anatomy and embryology. What is of real interest in these developments is the gradual replacement of the term 'monster' with that of 'malformation'. Early in the nineteenth century the subject of malformations was established in its own right, and, in 1822, experimental teratology began with Etienne Geoffroy Saint-Hilaire trying to produce malformations by jarring, pricking, varnishing, and inverting chicken eggs. By the second half of that century, experimental teratology and experimental embryology were firmly established; publications proliferated and an almost infinite variety of malformations were described not so much in descriptive terms as in terms of an etiology of malformations (Barrow 1971:119-20). Warkany characterizes the nineteenth century as the period when the science of teratology peaked; not before, nor since, have malformations in humans been so intensively studied:

... in systematic and taxonomic teratology the masters of the nineteenth century have not been equalled by their successors and much known to these scientists has been forgotten, as shown by some of the rediscoveries of recent times. (Warkany, 1971:19)
The rediscovery of Mendel's (1865) laws of heredity in 1900, and their application to human beings, led to genetic explanations which indicated that the origins of many malformations dated back to events that occurred generations before conception. By mid-twentieth century, genetic theory had supplanted all previous explanations which had constituted the etiology of monsters and malformations (Barrow, 1971:120).

The change in terminology which accompanied the development of scientific teratology signalled the rejection of mythological and theological accounts of the anomalous body for naturalistic explanations based on empirical observation. Concomitant with this etiological shift is the gradual usurpation of theological authority over the monstrous body by the practitioners of medical science who claim privileged knowledge about the human body and its pathologies. Monsters, now 'congenital malformations', are redefined as diseased, and, as such, become suitable objects for study and experimentation in order to effect a cure. This subjugation of human anomalies to medical authority is examined in depth in the following chapter.

Modern science, however, while providing new information on the mechanical aspects of how monsters are produced, does no better than Renaissance science in answering the question why? So much so, that Dr. Warkany warned his colleagues that, 'at present, the gaps between the biochemical concepts of mutation and the facts of congenital malformation are immense and bridged mostly by beliefs and speculations' (Warkany, 1971:26). This might explain why many people with physical malformations (irrational bodies?) were part of what Foucault (1961), calls the 'great confinement' which swept Europe in the seventeenth century; why many of those, whose ontological status is beyond Nature, remain today confined in those special kinds of zoos for disabled people. The failure of science to explain why, might also go some way in explaining why the perception of the anomalous body as monster, as a site of supernatural information, has persisted throughout history, and why, until relatively recently, it has been continually exhibited for a paying public to gape at and ponder the deep mysteries contained therein.
FROM MONSTERS TO MIRACLES OF NATURE

A note on the literature

Given the predominance the body has achieved in the last decade as a site worthy of sociological inquiry, and not forgetting the energy invested in the study of deviance and abnormality in the recent past, it is surprising that very little has been written about the physically anomalous body, its social location, and the anomalous subject. Bryan Turner (1984), in his seminal The Body and Society, ignores the anomalous body, only two (Oates, Bompiani) of the forty-eight contributions in the three volume Fragments for a History of the Human Body, edited by Michael Feher, Ramona Naddaff, and Nadia Tazi, would qualify, and Frank (1990, 1991), medicalizes the anomalous disabled body by analysing it alongside the 'ill' body. Of the works published specifically on anomalies, only Clair (1968), Fiedler (1978), and Bogdan (1988), move beyond a preoccupation with physiological characteristics to examine the social and psychological contexts in which freaks and the freak show became a possibility. In his survey of the literature Bogdan reports that Durant and Durant (1957) and Drimmer (1973) do not move much beyond the physiological\(^9\). This is certainly true of Howard (1977) and Parker (1983), which draw heavily on Victorian literature, most notably George Gould and Walter Pyle's Anomalies and Curiosities of Medicine\(^10\) (1896). Other Victorian manuals and medical reviews, as well as medical journals of this century, are marshalled to reveal the most intimate physiological details of the subjects embodied in grotesque forms. As such, these works, especially Howard and Fiedler, obtain a quality which amounts to a curious combination of attraction and repulsion. On the one hand there is an incitement to voyeurism with the medicalized presentations inviting the reader to don a white coat and invade the physiological privacy of the individuals under discussion: ones' curiosity is aroused. On the other hand, this prurience combines with the objective horrors of the physiological anomalies and the tragic situation of the subjects concerned, to repel the reader. One can also not help but feel implicated in the extension of the exploitation of these people by virtue of reading these texts.

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\(^10\) According to Howard (1968), this massive volume of very nearly a thousand pages, culminates the great age - the Victorian period - for detailed and reliable research into teratology.
Interestingly, the most sociologically useful work of the texts mentioned is by Bogdan who focuses on the historical, social, and intellectual contexts in which the freak and the freak show became a possibility rather than physiological detail. Similarly, Clair’s (1968) Human Curiosities, is useful insofar as it provides a history of the English Fairs complete with contemporary biographies, publicity material, and reflections on the curiosities per se and their conditions of work. This information provides valuable insights into the social perception, location, and possibilities of the anomalous body during this period.

The English Fairs and the ‘Raree Shows’

In the tenth century, the domestication and commercialization of monsters begins with the display of Miracula naturae (miracles of nature) at Bartholomew Fair to a paying public. In 1133 Henry I had granted a charter to hold a three day fair at Smithfield beginning on the eve of the feast of Saint Bartholomew; proceeds were to support the Priory, Hospital, and Church of Saint Bartholomew. By the reign of Queen Elizabeth I, the three day fair had grown into a fourteen day carnival. Bartholomew’s Fair was discontinued in 1855. Throughout its seven centuries a main feature of the Fair was the ‘raree show’ featuring displays of the anomalous body which Aristotle had called lusus naturae or jokes of nature. Such creatures, therefore, ought be seen as sources of amusement, rather than terror, and the showing of them for profit to the public was considered quite within order.

A quote from Robert Southwell, the Norfolk poet, in a letter to his son dated August, 1685, captures the regard with which the exhibits, and, implicitly, the exhibitors are held:

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\text{Others, if born in any monstrous shape, or have children that are such, here they celebrate their misery, and, by getting of money, forget how odious they are made. (Clair, 1968:2)}
\]

Southwell obviously feels pity for the unfortunates who have little choice but to display themselves in all their monstrosity if they, and their managers, are to survive. However, reading between the lines, we see that his sensibilities are offended both by what he must view and by the manner of the human curiosity. On stage these monstrosities seem to forget that the reason people are paying to see them is no cause for celebration. When the audience has safely departed, the exhibit will be alone, trapped in a monstrous body, the moment of glory passed. People will continue to stare, only, now, without paying. Nothing has changed. They remain travesties.
In his account of Bartholomew Fair, historian Henry Morely comments tellingly on the extent and relish for anomalies:

The Kings and Queens of Europe, in the years before and after 1700, shared in the taste of all classes, for men who could dance without legs, dwarfs, giants, hermaphrodites, or scaly boys. The taste still lingers among uncultivated people in the highest and lowest ranks of life, but in the reigns of William and Mary it was almost universal. (Morely cited in Clair, 1968:3)

Giants and dwarfs from around the world were regularly exhibited as MIRACULA NATURAE (Miracles of nature) at Bartholomew. As such, they were not to be pitied but viewed in wonder and awe - a point which escapes the aforementioned Robert Southwell. These wonders could also be seen regularly at a number of places around London, including Southwark from 1550, Charing Cross from 1644, and West Smithfield in 1677. Besides giants and dwarfs, hairy people and Bearded Ladies¹¹, ‘armless wonders¹², and fat men and women were other wondrous attractions.

A description of the anomalies, the mode of presentation, and the reception they received from the audience attending Greenwhich Fair, an annual event, appears in Sketches by Boz, first published in 1835:

The dwarf are also objects of great curiosity, and as a dwarf, a giantess, a living skeleton, a wild Indian, “a young lady of singular beauty with perfectly white hair and pink eyed”, and two or three other natural curiosities, are usually presented together for the small charge of a penny, they attract numerous audiences. The best thing about a dwarf is, that he has always a little box, about two feet six inches high, into which, by long practice, he can just manage to get, by doubling himself up like a boot-jack; ...Shut up in this case, the unfortunate little object is brought out to delight the throng by holding a facetious dialogue with the proprietor, in the course of which the dwarf (who

¹¹ The seventeenth century seems to have been a most favourable time for bearded females: Margaret of Parma, Regent of the Netherlands from 1599 to 1667, was bearded; King Charles XII of Sweden had a bearded female grenadier in his army; John Evelyn (1651) enters in his Dairy, a description of a woman with ‘a very long lock of hair out of each ear...a most prolix beard and mustacheos, with long locks flowing on ye middle of the nose’ (Fiedler, 1978:144); the diarist Samuel Pepys, 1688, reports seeing in Holborne, London a ‘plain little woman’ with a beard ‘black and grizly... bushy and thick’ (Parker, 1983:95).

¹² Phocomelics (later known as ‘seal children’ in the American freak show), that is people with vestigial hands and feet attached directly to the torso, who, nevertheless, amazed their audiences with displays of calligraphy, shuffling cards, playing musical instruments. Most famous was the German dwarf Matthew Buchinger (b.1674) who was patronized by George I, and who exhibited himself throughout the British Isles (Clair, 1968:132-6).
is always particularly drunk) pledges himself to sing a comic song inside, and pays various compliments to the ladies... (cited in Clair, 1968:92)

Boz notes the humiliation of the performing dwarf: he can only sell his body if drugged. In this respect he is not unlike today's prostitutes who resort to drugs so that 'stoned', disembodied, they sell their bodies but not themselves. Adding to the humiliation is the apparently common practice of transporting dwarfs from venue to venue in little boxes. This was probably a major plank in the construction of a particular stage image for the exhibit, as evidenced by the letter written by a showman to the Spectator, 1712 (ibid.:96). However, it was a mode of transportation fraught with danger, as the Swiss dwarf Wormbergh discovered in 1689. As his box was being loaded the plank between quayside and ship broke; the porter swam clear, but the dwarf drowned. Undoubtedly his manager was upset at having lost a lucrative exhibit, but what is indicated is the underlying disdain in which the anomalous body was held: something essentially non-human, a mere exhibit, to be crated and boxed when not in use.

During the winter months human curiosities shifted inside to the upstairs rooms of taverns and coffee houses where they were exhibited during the off-season. The 'attraction' of the anomalous body grew throughout the eighteenth century with thousands of spectators paying to view any anomaly. But the showman's main source of income was derived from private showings arranged for the nobility and gentry, people who preferred to be excited in the seclusion of their own homes.

**The European Court Dwarfs**

Dwarfs have always been in demand by the elite as entertainers. But it is during the Middle Ages and the Renaissance that the nobility's fetish reaches its zenith when dwarfs are granted a privileged space in court society. The court jesters of the fifteenth, sixteenth, and seventeenth centuries are often dwarfs; dwarfs who frequently combine wit with wisdom, dwarfs who distract with their antics yet counsel with their advice. Court dwarfs as jesters are, thus, permitted unlimited freedom of speech; their mockery fulfils two important functions in the court. On the one hand they deflated sycophantic courtiers with their buffoonery as

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13 Dwarfs entertained the Pharaohs and high dignitaries of ancient Egypt, and while most belonged to a class of minstrels and jesters, a few achieved a measure of importance, as in the case of Khnuhotpu, whose tomb was one of the finest excavated at Saqqarah during the nineteenth century. Dwarfs were kept as servants and treated as household pets by the Romans. The Emperor Augustus liked having Midgets around him, so long as they were young and perfectly formed. A band of grotesque dwarf gladiators performed at the Colosseum (Clair, 1968; Fiedler, 1978).
well as unearthing and publicising the corrupt, as in the case of Brusquet, King Francois I's fool. When the King and his counsellors were strategizing to recapture Calais from the English, Brusquet advised: "You need only send X... (a courtier not remarkable for his probity). He will take Calais for you. There's nothing he won't take!" (Clair, 1968:78).

On the other hand, the court dwarf, in the guise of jester, is able to inform the King of holes in his clothing which others fear to bring to his attention. For example, in 1539 Triboulet, another of Francois's Fools, was able to relay criticism of his allowing the Spanish Emperor to pass through France to suppress a rebellion in Ghent, rather than making him go by sea. Seeing Triboulet writing down the name of Charles V, the King asked his Fool the meaning. Clair quotes the reply: "I am writing down the name of the Emperor...because he is a fool to pass through France." "And suppose I allow him to do so" queried the King. "Then ...I will rub out his name and substitute yours" (1968:76). Howard (1977), reports that this function of the court dwarf was so valued that one of the kings of Denmark appointed one of his dwarfs prime minister to get at the truth about the political situation which other men were afraid to utter. While the keeping of official court Dwarfs had died out by 1662 in Western Europe, the practice continued in Russian courts into the nineteenth century (Clair, 1968:70).

From these accounts we can see that during the fifteenth, sixteenth, and seventeenth centuries some dwarfs were able to assume positions of power within the world of normals. As court jesters and Fools they were granted the ear of the king, and once acquired some quickly moved up from mock commentator to that of real advisor. A few used their positions to amass wealth, as did Archibald Armstrong, jester to James I and, later, to his son Charles, who extracted rich presents from those who wanted him to act as intermediary for the presentation of petitions to the King (ibid.:59). Occupying such a pivotal position in the court, many jesters could not help but make powerful enemies, and their safety was always dependent upon the King's good favour.

Other dwarfs were kept by ladies of the court and in the houses of the nobility as servants and companions, as distractions and playthings. Catherine de' Medicis had six dwarfs (Fiedler, 1978:48); Marie-Theresa, Spanish wife of Louis XIV, was entertained by six 'dwarf-fools' (Forster, 1985:xliii), one of whom was described as a 'monstrous creature' (Clair, 1968:73); while in Rome in 1556, Cardinal de Vitelli used thirty-four 'small, but [mostly] ugly and misshapen' dwarfs as waiters at a banquet he was giving (ibid.:72). The Russian nobility
was especially taken with dwarfs, and the use to which the Russian nobles put them is probably indicative of the dwarfs' function in the rest of European court society. Clair cites Captain C.C. Frankland from his Visits to the Courts of Sweden and Russia (1832):

Madame Divoff, like many other Russian ladies has a dwarf in her house who remains constantly in her company. He is less ugly and disagreeable than others of his species. Princess Gallitzine has a little fellow of this sort: the Lisianskis also have one in constant attendance. The pretty Mlle Rosetti, two evenings ago, kept caressing the dwarf at madame Divoff's ball. "Beauty and the Beast," said I to her.... (emphasis added, Clair, 1968:70)

Dwarfs are not considered completely human: they belong to another species. This is in keeping with early European legends that assign a common origin to Pygmies (Dwarfs) and monkeys. One claims both were made from the clay left over after God had fashioned women around Adam's rib. Another, more commonly held, posits them as beast/human hybrids, the issue of unnatural coupling with 'lower animals' in defiance of God's law. This theory is confirmed in the late Middle Ages when monkeys are kept alongside dwarfs as domestic pets in the courts of Europe (Fiedler, 1978:72-3). Dwarfs are on a par with monkeys: both constitute a degenerate form of humanity. However, a patronizing attitude is adopted, particularly towards dwarfs, who will, in return for the protection of the court, perform a variety of services. Not only will they entertain as Fools, but they will also be servants, while all the time acting as foils to the beauty of the young and beautiful women of the court.

Fiedler (1978:69-78) explores the association of dwarfs with lower animals by way of an examination of the high art of the sixteenth and seventeenth centuries. When painters such as Raphael, Velasquez, Coello, and Goya, show dwarfs with dogs, as they so frequently do, the message is unambiguous: the dwarf's entire being is saturated with perversity. According to Fiedler, the dog, the housebroken wolf, long associated with the Devil, was a symbol for sexuality and aggression. The dwarf, like the dog, was 'domesticated but unsubdued' (ibid.:76).

In Victor Hugo's Le Roi s'amuse, the icon is represented in words with the play's main protagonist, Triboulet, the hunch-backed, dwarf-jester of Louis XII and Francois I, being described thus:

14 Who were described as, 'generally well-shaped and their hands and feet are particularly graceful [unlike] the clumsy deformed dwarfs ...exhibited at our fairs in England' (Porter cited in Clair, 1968:69).
Triboulet is deformed: Triboulet is a sick man; Triboulet is the court fool, a wretched combination of circumstances which rendered him malevolent. Triboulet hates the King because he is a king ... all men without a hump on their back.... He corrupts the King, dulling his moral faculties, and lets him loose among the families of his nobles, pointing out the wife to seduce, the sister to abduct, the daughter to dishonour... (cited in Clair, 1968: 74)

The court dwarfs are, thus, characterized by ambiguity. On the one hand they titillate and entertain, on the other they represent corruption and subversion. This, perhaps, explains why the court dwarfs were treated as pets and tolerated as such. They were kept primarily for their entertainment value, playthings to amuse and distract. But as a degenerated form of humanity, dwarfs were intrinsically amoral, profane creatures who had to remain submissive to those in charge. Thus, ultimately, the only way in which the court dwarfs differed from the anomalies exhibited in the fairgrounds, was that the space they occupied was privileged - a space within which they were afforded, within limits, the protection of the nobility and the relative freedoms that accrued. Freedoms that contrast sharply with those 'human marvels' who could only make a living by exhibiting themselves in the courts and fairs of Europe between the sixteenth and nineteenth centuries.

**Human marvels**

It certainly was not a matter of 'bright lights, big cities' for these anomalies: they, and their managers, survived only so long as the public was willing to pay to see their abnormalities. Some failed from the word go, as in the case of the Irish dwarf, Owen Farrel, who went to London to make money exhibiting himself. The project failed and he was forced to beg on the streets until a short time before his death when he gained a weekly allowance by selling his body to a surgeon. In return the surgeon gained dissection rights, which were duly taken up in 1742 when Farrel died; the skeleton was preserved in the collection held in the anatomy department at Glasgow University.

Over time, social attitudes change and bodies age. Formerly successful exhibits lose their erotic appeal and fall on bad times. For example, the Polish dwarf, Count Boruwlaski, celebrated throughout Europe, began his career as the protege of Countess Humiecka who took him around the courts of Europe, where he entertained the nobility and lived off their generosity. Later, after falling out with his patroness, he was forced to tour European courts, giving 'concerts', and becoming a kind of 'lap dog' to the ladies who insisted on taking him on their laps where he was fondled, caressed, and kissed. In 1782, he moved to England, where, according to Fiedler, Puritanism and Victorianism had struck a death blow to the cult
of the Dwarf and anomalies were now prized more as curiosities than erotic playthings. Under this new figuration, Boruwlaski was forced to exhibit himself as a Freak to a paying public in his own house.

Others succeeded, but over-exploitation led to degeneration and death. For example, the following description of the Welsh midget Hopkin Hopkins near the end of his career as a 'Miracula Naturae', appeared in the Philosophical Transactions, of the Royal Society, Vol. 47, 1751:

I went along to view and examine this very extraordinary ... but melancholy subject, labouring under all the miseries and calamities of very old age, being weak and emaciated, his eyes dim, his hearing very bad, his countenance fallen ... his head hanging down before, so that his chin touched his breast: consequently his shoulders are raised and his back rounded, not unlike a hump-back. His teeth are all decayed and rotten except one foretooth below. (Clair, 1968:106-7)

It is clear from this description that Hopkins was still being exhibited in decrepitude and old age; a more wretched and crestfallen image of a person is difficult to imagine. That is, until the life of Julia Pastrana, the 'gorilla-woman', is considered.

Exhibited as the 'Ugliest Woman in the World', Pastrana, according to Howard (1977), represented the height of Victorian grotesque. So extraordinary was her appearance that she was submitted to Charles Darwin for authentication. His description follows: 'This woman has a strong beard, very hairy body, particularly on the forehead and neck and, a phenomenon of particular interest, an irregular double row of teeth in the upper and lower jaw which gave her a prognathic appearance and a simian profile' (Howard, 1977:17). Pastrina fell in love with her manager who, rather than lose his lucrative exhibit, married her. Soon she was expecting a baby which was eventually born very hairy but physically doomed; it had been a difficult birth and Julia lay dying. Socialites paid to file past her deathbed for a final glimpse of the 'gorilla women'. But they need not have worried. Her manager-husband had no intention of allowing two lucrative exhibits to rot in the ground. As soon as she died he had both Pastrina and her baby stuffed by a taxidermist, and exhibited them all over Europe, clothed in shoddy stage tinsel and decked in artificial jewellery. Even after her death Pastrina was made to suffer the tragedy of being 'other' during an age of perverted curiosity in the anomalous body.
At least Pastrina didn’t live in fear of what would happen to her once she died. This was not so for the Irish giant O’Brien (1760 - 1806), who was hounded throughout his life by surgeons wanting to dissect him. According to Howard (1977), this was not uncommon during the reign of Victoria when medical researchers acted like body snatchers, hunting down their intended subjects long before they died. O’Brien was only one of many ‘sensitive giants,’ who ‘lived in morbid fear of dissection’ (Howard, 1977:97; see also Clair, 1968; Fiedler, 1978; Parker, 1983).

Today, with the advent of ‘brain-death’ and the organ bank, skeletons no longer interest medical science so much as living corporeal material. Indeed, we are forced to confront our bodies and rethink the uniqueness of our corporeal selves as we stand on the threshold of the recyclable body. So too, the eighteenth and nineteenth century Americans when confronted with ‘freaks’ of outstanding proportions.

AMERICAN EXCESS: THE FREAK AND THE FREAK SHOW

When the Soccer World Cup was staged in Los Angeles, USA in 1994 it differed from all preceding World Cups in terms of venue, organization, commercialization, and presentation. The world was hit with a media barrage of razzmatazz, hype, hard-sell, exaggeration, expert opinion, staged presentations, and commentary on a scale befitting the home of capitalism and visual imagery. Football and the World Cup will never be quite the same. In the eighteenth and nineteenth centuries, a similar transformation occurred when the Americans began staging their version of the English raree show: ‘Miracles of Nature’ underwent a metamorphosis and emerged as ‘freaks’, and their place of exhibition became the ‘freak show’.

From about 1840 through 1940, people with physical, mental, or behavioral anomalies were formally shown in travelling circuses (for example, Ringling Brothers, Barnum and Bailey Circus), carnivals, museums, and amusement parlours throughout America. The anomalies were generally categorized as ‘freaks’ and their place of exhibition the ‘freak show’. Exhibits included Dwarfs (achondroplastic dwarfism), Midgets (hypopituitary dwarfism), Giants, Pin Heads (microcephalics), Half men/half women (hermaphrodites), Siamese twins, people with supernumerary heads and limbs, ‘One-and-a-Halfs’, that is, a perfect body from which hung an incomplete parasitic body, generally issuing from the region of the belly (thoracopagus
epigastricus), legless and armless wonders (phocomelics), fat people, human skeletons, hairy people including Bearded Ladies and hirsute men (Brachman-DeLange syndrome), people with skeletal dysfunction and skin disorders, and albinos. Cannibals and savages, wild men and women from exotic and far away places were also exhibited as freaks, as were a variation of the latter known as ‘gloaming geeks’, usually a desperate drunk or drug addict, who was put in a pit where he would bite off the heads of rats, chickens, or snakes and then drink the blood. Finally, self made freaks, like tattooed men and women and otherwise normal humans able to swallow swords, eat flames, thrust spikes up their noses, were also permissible alternatives to congenital malformations in the freak show (Fiedler, 1978; Bogdan, 1988).

Writing in the mythological, psychoanalytic tradition Fiedler (1978), argues that the anomalous body taps deep psychic fears and needs within us. Dwarves and giants, he asserts, awaken in us the primordial fears of scale we had as children - that we would not grow up, and the monstrosity of adults; hermaphrodites tap the dream of androgyny arising from the way each sex is defined as freakish in relation to the other; hairy people compound doubts about our place on the evolutionary scale, especially women who are encouraged to regard hair on the face and legs, between their breasts, or in their armpits, as excessive and by implication not human (Fiedler, 1978:27-36).

But the anomalous body not only repels it also attracts. All freaks, according to Fiedler, excite an erotic response within us. And the freak show legitimates the impulse to gawk at the bodies which arouse ‘freaky’ desires ‘of breaching the last taboo against miscegenation’ and ‘a longing for degradation’ (ibid.:137). Much of the chapter on the eros of ugliness is spent detailing in word and picture genital abnormalities (ibid.:138-43) which were never exhibited in public. Rather, Fiedler dredges them up from medical textbooks (ibid.:139) and includes them, no doubt, to tap the reader’s ‘deep psychic fears’. Again, in his chapter on Hermaphrodites, Fiedler returns to the medical library for photos, inducing in the reader a sense of unease, a hint of the pornographic, a feeling that Fiedler, the voyeur, is playing his own psychological game. Indeed, this is the impression one is left with, particularly when one recalls his introductory comments in which he laments the decline of the freak show: he is of the last generation ‘whose imaginations would be shaped by a live confrontation with the nightmare distortions of the human body’ (ibid.:16).
For Fiedler, then, the 'freak', the anomalous body, is more than a physiological condition; it forces us to confront our deepest psychic fears about self and our corporeal boundaries. However, his use of depth psychology to assert that the freak reveals a 'Secret Self' (ibid.: 315) is as much a mystification of the anomalous body as the ancient Babylonians' assertion that future events could be divined from abnormal births (Warkany, 1959:85). We are no further in understanding the 'freak', or the social, political, and historical conditions under which the 'freak', the 'freak show', and the mass interest in freaks became a possibility. Also, if the 'freak' is an archetype that arouses a deep, rudimentary, and lasting psychic fear, how can Fiedler account for the many marriages between unusual exhibits and their normal peers, which Fiedler himself notes (1978:147, 170), or the success with which freak/freak married couples (for example, the Bates in Bogdan, 1988:207) were integrated into their local communities?

Robert Bogdan (1988), poses more useful questions in his book *Freak Show: Presenting Human Oddities for Amusement and Profit*. In this text the physiological characteristics of the various exhibits are incidental. Rather, the focus is on the social arrangements under which the anomalous body was constructed as the 'freak' at this particular moment in American history.

**Historical/social context**

It was not until the eighteenth century that Americans had their first encounters with beasts from the deep and mysterious interiors of far-off lands, including parts of America which had yet to be fully explored. Individual entrepreneurs toured the country showing 'animal curiosities' such as elephants, lions, giraffes, and, after 1860, the gorilla. At the same time showmen were travelling from town to town promoting and exhibiting physically disabled people as 'human oddities'. Animal and human oddities were frequently exhibited conjointly as 'living curiosities', which were, according to Bogdan, beyond the ken of the eighteenth and early nineteenth century American. At the turn of the century these single attractions began to be formally organized into freak shows attached to larger organizations.

'Cabinets of curiosities' were first exhibited in the early museums as side shows designed to attract the extra custom needed to keep the museum solvent. These museums eventually failed and were replaced with a new form which, while retaining the respectability of the museum, was devoted to entertainment and amusement. The first, and most successful, was P. T. Barnum's American Museum (1841), where 'human curiosities' were the main attraction.
Between 1870 and 1900 a cheaper version, the dime museum, proliferated to meet the entertainment needs of the European immigrants who were then pouring into the cities across America. Again the freak show dominated as the main attraction, but it was tarnished by the cheap and sleazy forms of entertainment many of the dime museums offered. Also, managers often promoted 'the shabbiest of human oddities and gaffed [faked] freaks as scientific sensations and singular attractions...they raised fraud, misrepresentation, and exaggeration - the hard sell - to new heights' (Bogdan, 1988:37). By the twentieth century, the dime museums were in a state of decline as they succumbed to attacks from progressive reformers, bad publicity exposing the fraud and duplicity, and competition from other, more respectable forms of entertainment - circuses, street fairs, state fairs, world fairs, carnivals, urban amusement parks - all of which promoted the freak show as a major attraction. Indeed, the freak show was considered central to the financial well-being of many of these operations (ibid.:40-62).

**Intellectual context**

It would be wrong to assume that the conditions for the promotion and display of the anomalous body were made possible solely by the efforts of exploitative showmen out to make a quick profit. Rather, a fuller picture reveals the creation of 'freaks' as part of the scientific enterprise of the day in which the anomalous body became a prime site of investigation as physicians and scientists alike struggled to understand the pathology and taxonomy of the human body. Throughout the eighteenth and nineteenth centuries, debates raged within the scientific community over the taxonomy of the 'human oddities': were they examples of new and unknown 'races' or were they 'lusus naturae', that is, nature's jokes or mistakes? The former was supported by tales of explorers who claimed to have discovered new races in far-off lands and by the importation of tribal peoples complete with their cultural accoutrements. In turn, these strange and exotic 'savages' spurred the popular imagination into a belief in races of tailed people, dwarfs, giants, and even people with double heads. Physicians, for whom teratology had become a fad, concerned themselves with the scientific classification of lusus naturae. Darwin changed the direction of the debate with his publications *Origin of Species* (1859), and *The Descent of Man* (1871): what then became significant was in deciding where the various categories stood in relation to each other in the great chain of being. We can also imagine the same sense of unease resurfacing about the immutability of human corporeality which Le Brun had earlier provoked with his catalogue showing the interchangeability of animal and human physiognomies. According to Bogdan,
the fascination Victorian Americans had for primates reached new heights: ‘Darwin and gorillas were the talk of the day’ (ibid.:138, see also Fiedler 1978).

**Social construction of the freak**

It is at this point that science most clearly merged with showbiz to create the ‘freak’ and the ‘freak show’. Showmen were quick to capitalize on public interest by manufacturing exhibits that exemplified various aspects of the debate. The long and profitable career\(^\text{15}\) of William Henry Johnson, a black man with microcephaly, neatly encapsulates all aspects of the ‘freak’ and ‘freak show’ phenomenon. Even though his body was relatively unspectacularly anomalous (short and lacking a forehead with his large nose connecting directly with the top of his small head), he was reconstructed and presented as a freak of outstanding proportions and scientific merit. His anomaly was emphasized by keeping his pinhead closely shaven except for a topknot; an account of his origins, consistent with the scientific theories of the day, was fabricated and used by his manager to variously promote Zip as the ‘What Is It’, ‘The Monkey Man’, and ‘The Missing Link’. According to Fiedler (1978:165), ‘Zip was, in short, a triumph of packaging and ‘humbug’; a creation, which in mirroring the social Darwinism of the day, appealed to and exploited the public’s prejudices, stereotypes, disdain, and contempt for the black (Bogdan, 1988:135).

In contradistinction, the eight foot eleven inch Robert Wadlow refused to become a freak. When he eventually did agree to appear for the Ringling organization he stipulated in his contract that he would only appear at the Madison Square or Boston Gardens, for three minutes twice a day in the centre ring. He would not appear in the sideshows and always in a business suit. Wadlow refused to be recreated as a freak, leaving Bogdan to comment: ‘Although very tall, he was not a giant’ (1988:274).

While Wadlow obviously knew who he was and what he was doing, questions remain about other freaks’ sense of self; was the freak an exploited object?; or was the freak a subject who could separate him or herself from his or her invented stage persona? In other words, did the discipline each anomalous body was subjected to as a specific exhibit produce a particular subject?

\(^{15}\) Over sixty-seven years an estimated one hundred million people viewed Johnson.
Yes, according to Bogdan. Rather than analyzing the anomalous body in terms of physiology, he looks at freaks in terms of mode of presentation, the discipline and type of anomaly associated with each mode, and the type of subject produced. Bogdan identifies three modes: exotic, aggrandized, and respectable.

The exotic freak

'Zip' Johnson exemplifies the exotic mode which preyed upon the public's interest in the primitive, the bestial, the culturally and physically strange. Microcephalics and achondroplastic dwarfs were most likely to be cast in the exotic mode. The mental retardation, small stature and pointy heads of the former, and the lack of proportion between the head, limbs and trunk of the latter made them ideal 'missing links' or atavistic specimens of an extinct race. Black Americans also tended to be cast as exotic 'missing links' and imported tribal people as 'Cannibals and Savages'. What made these exhibits freakish was their cultures, appearances, and the deliberately outrageous fabrications of their managers (ibid.:176-99).

Since many exotic exhibits were mentally retarded it is difficult to state with any certainty whether or not they were able to distinguish themselves from their mode of presentation. However, since many were purchased, trained and presented while still young children, they probably knew no other life, or state of being, and identified with their stage personae. The exotic, non-Western exhibits, however, would clearly have seen their on stage personae for what they were and constituted themselves quite differently. Nevertheless some did become 'showmen', for example, Cliko, 'The Wild Dancing South African Bushman', while others, like the Ubangis, subjects in their own right, led miserable lives.

The aggrandized freak

In contrast to the exotic mode, which highlighted difference and inferiority, the aggrandized mode of presentation emphasized status and superiority. Apart from their anomaly, such freaks were cast as high status persons possessing pedigree, position, talents, and achievements. They were bestowed with titles such as 'General' or 'Queen', connections with high-society were exaggerated or fabricated, as were snobbish attributes and pastimes such as being highly educated, multi-lingual, writing poetry, etc. Clothing completed the facade - expensive jewellery, furs, evening gowns, top hats and tails, canes - as did their performances which emphasized their hyped superior talents in acting, impersonation, singing, dancing, and playing musical instruments. While Midgets (for example, Charles
Stratton aka 'General Tom Thumb' and his midget wife Lavinia Warren, the Horvath Midgets, Singer's Midgets) were the preferred anomaly for aggrandized presentation, some Siamese twins were also aggrandized, for example, the Hilton Sisters (Bogdan, 1988:108-75; see also Fiedler, 1978; Parker, 1983).

Many of the aggrandized freaks did become wealthy and famous, and, like the royal dwarfs of Europe, became fashionable in high society and showbiz circles. Unable to distinguish between illusion and reality, many, according to Bogdan, reconstituted themselves in terms of the fabricated stories and hype used in their presentation. He concludes that they were deluded and it would have been better for them to constitute themselves as their audiences did, namely 'as the caricatures of elite adults, as freaks first and performers second' (Bogdan, 1988:175).

In reaching this conclusion, Bogdan fails to consider the corporeity and the politics of the situation. By appropriating the subjectivity consistent with the aggrandized presentation, Midgets, those 'diminutive', childlike anomalies, were able to escape infantilization and to constitute themselves as adults of some consequence. From this viewpoint, the possibility that these people were politically active subjects follows: subjects who chose to be 'aggrandized' to reap the accompanying material and psychological rewards.

**The respectable freak**

Bogdan's third mode of presentation, *respectable freaks* was open to all types of anomaly. The 'respectable' giants and giantesses, bearded ladies, living skeletons, armless and legless wonders, and Siamese twins, had no difficulty in separating stage persona from real self: the emphasis was on the ordinariness of their lives in spite of their anomalies. All that was required of these exhibits was that they be clean, neat, and respectably dressed and that they perform mundane tasks such as finding a spouse and giving birth, armless wonders cut out paper dolls with their toes, legless freaks demonstrated their ambulatory skills. These everyday events were then construed as outstanding achievements which transformed these ordinary people into human wonders.

Alternatively, the respectable freak's moral superiority could be stressed. Having overcome insurmountable odds, they were surely living examples of the Lord's work? For example, Ann E. Leek Thompson, an armless wonder, was known for her piety and religiosity. In her publicity photographs she is pictured with her husband and son, sitting on a mat which she
had elaborately crocheted and embroidered with religious symbols and quotes from scripture. The imagery conveys the essence of Victorian respectability (Bogdan, 1988:200-33).

Despite Bogdan’s three categories, not all freaks were able to be comfortably slotted into any particular one (for example, see Krao in Howard, 1977; Fiedler, 1978; Bogdan, 1988; and the Bates in Parker, 1983). This requires a consideration of freaks within the overall context of the travelling circus, carnival, or dime museum, and how the personnel of these institutions constituted themselves in relation to the wider social context.

**The freak as showman**

Having no fixed abode, trade or occupation in the normal sense, the itinerants with the travelling circuses were always regarded with a mixture of suspicion, contempt, and hostility; as shysters out to defraud the respectable citizenry of the towns they visited. Very quickly circus personnel began to constitute themselves as showmen whose legitimate task was to separate the ‘rubes’ from their money by trickery and deception. In this context, Bogdan argues that any corporeal abnormality was viewed in terms of its money-making potential for both the exhibit and other showmen who could manage, promote, and present the freak. And while they didn’t occupy the highest rung of the amusement world’s own stratification system, Bogdan says freaks were a welcome and taken-for-granted part of the culture.

Moreover, there is no evidence to suggest that exhibits took their category name, ‘freak’, either personally or seriously. Freak did not have the same discrediting connotations then as it does today. Within the amusement world it was just a small part of a larger deception - for example, the ‘abundantly fraudulent’ exotic and aggrandized modes of presentation - aimed at parting the rube from his or her money. And so long as the title ‘freak’ kept the money rolling in, that was all that mattered. What was important for the freaks within the amusement world was that they were able to constitute themselves as showmen who:

As freaks sat on the platform ... look[ing] down on the audience with contempt - not because they felt angry at being gawked at or at being called freaks, but simply because the amusement world looked down on "rubes" in general. Their contempt was that of insiders towards the uninitiated. For those in the amusement world it was the sucker who was on the outside, not the exhibit. (Bogdan, 1988:272)

Within this context some freaks were able to achieve some degree of independence. The more popular and competent exhibits negotiated favourable terms of contract, earning a
comfortable living, some becoming very wealthy. Yes, some were exploited, but Ward Hall, former freak show manager, contends that many managers had a business relationship with their human oddities in which both sides were dependent on the other for their respective livelihoods. By virtue of this, freaks were accepted as showmen in the amusement world and respected 'for parleying into an occupation what, in another context, might have been a burden' (Ward Hall cited in Bogdan, 1988:268). Implicit in this statement is the view that the anomalous body as freak, acquired a relative independence and freedom within the amusement world which was not possible in other social contexts.

NEW ZEALAND: THE CIRCUS AND THE FREAK SHOW

Because the data is both meagre and sketchy, it is difficult to ascertain with any degree of certainty whether or not the 'freak show' was a part of the circuses which have toured New Zealand since 1852. In the advertised programme for Rowe's Olympic Circus (New Zealander, 27/3/1852:2), the public of Auckland is invited to be entertained by performances of this 'well known and celebrated Equestrian Company and highly trained stud of horses.' It is to be wholesome entertainment. No mention is made of any sideshows; all the action will take place in the ring, beginning with Mr Rowe leading a 'Grand Eclair Waltz-Entree on 6 horses' and concluding with Mr Howard and the 'Highly Laughable after piece "The Miller and the Coal Man" in which the beautiful black man "Orthello" will be introduced' (ibid.). This may have been a way of smuggling a freak into the show, but the advertising seems to indicate racist farce rather than freakery. However, thirty-eight years later reference is made to 'numerous sideshows' in an advertisement for Wirth's Wild West Show (New Zealand Herald, 19/9/1890:5). It is to be a big event in colonial society: the sideshows and the ring will cover two acres, arrangements have been made with the Railway Commissioner to run a special excursion from Waikato, and the master of the SS Coromandel is offering a package which includes a return trip and tickets to the show for the people of Coromandel. In the following reviews (New Zealand Herald, 23/9/1890: 5 and 24/9/1890:4) much is made of the 'horsemanship, equitation, juggling and arobatism' but the sideshows remain cloaked in a prudish silence. This is surprising. Given the extraordinary nature of the event, one would expect all aspects to be reported. One is left wondering if the sideshows provided less than wholesome forms of entertainment? In an article reflecting on the history of a circus which regularly toured New Zealand, Wirth Brothers Pty Ltd, Allan Jeffries provides some tantalizing clues as to what those sideshows might have contained:
... generations of somersaulting baboons, bearded ladies, fat women, midgets, pin-headed Chinamen, the tallest and bravest men in the world, the human fly... and other show-business freaks with whom the Wirths have lived under canvas for generations. (Jeffries, 1963:3)

It seems that human freaks were a definite part of the Wirth Circus repertoire and that probably they were exhibited at some stage in New Zealand. While this can not be said with any certainty, the reference to 'bearded ladies' and 'fat women' does awaken distant childhood memories of seeing fat, bearded, and tattooed ladies in the sideshows of the Auckland Easter Show. All-in-all, New Zealand audiences seem to have been too conservative to offer exhibits other than from the least freakish end of the freak spectrum. Rather, the circus troupes which toured New Zealand (including Coles', Ridgeways, Whirling Brothers', Bullins' Circus, Chipperfield's Circus, Royal American Circus) seem to have concentrated their energies on providing entertainment based around performing animals, trapeze artists, jugglers, and clowns (McWilliams, 1963:42; Jackman, 1984:15).

This does not mean that New Zealanders were immune from the extremes of the freak show. It found its way here via magazines, newspapers, books, film etc brought in from overseas. And while Zealanders may never have condoned the freak show, they were certainly aware of its existence and purpose, especially the families and acquaintances of congenital malformations, the 'handicapped', 'cripples', 'spastics' etc. As such, the 'freak', the anomalous body, has always been very much part of our culture by virtue of the fact that it stands in opposition to the dominant cultural value of a fit, healthy, and rugged physicality born as much out of New Zealand’s physical environment as its social environment. Cultural values expressed in terms of pitting the body against nature or one another in contact sports: of subduing and breaking in the land to produce wool and butter, of tramping the great outdoors, of rucking and tackling hard on the rugby and soccer fields, not forgetting the close, physical game our 'girls' play on the netball courts. Underpinning the ideal of the physical, has been the Plunket ideology which promoted the breeding of fit, healthy, and intelligent children as the moral duty of all New Zealand parents since 1907. This is examined in greater depth in the following chapter.

SUMMARY AND CONCLUSIONS

In this chapter, the scientific and commercial interrogation of the anomalous body has been presented. The former proceeded from the cosmology of the ancient Chaldean priest-
astronomers through the monsters of Greek, Roman, and Renaissance physicians, the malformations of Victorian embryologists and morphologists, to congenital malformation and the genetic explanations posited by present day teratologists. Since Pare, the objectifying and dehumanizing affects of the scientific discourse around the anomalous body has contributed to its ongoing mystification and disqualification from the human realm. Indeed, if Dr. Warkany is to be believed, cosmological explanations are immanent within that discourse, and once deconstructed, the jargon of today's scientists does not advance our understanding of the purposes of the anomalous body very much beyond that of the ancient Babylonians. What the scientific discourse does tell us, however, is a lot about Western humanity, the ways in which we have explored, understood, and located anomalous, and hence, non-anomalous, corporeality in the cosmos and the world, universally and locally. In short, within science, anomalous corporeality, monsters, and congenital malformations, have continued to be posed in opposition to humanity and nature. In seeking to explain, to reorder, the anomalous body the scientific enterprise has reified it as an object worthy of surveillance and social control.

Commercial entrepreneurs have, in the meantime, exploited debates within science by firstly exhibiting anomalies as miracles of nature and then as freaks as the Natural order was gradually deposed by the scientific order. Miracula naturae were beings which inspired awe; exotic freaks developed and perpetuated the racist and imperialistic assumptions of nineteenth century anthropology when exhibited as specimens of inferior, subhuman 'races of man'; aggrandized freaks parodied America’s substitute royalty; respectable freaks propagated the White Anglo Saxon Protestant ideology that through sober-living, hard work and faithfulness in the teeth of adversity any body can attain the American dream. Despite the limitations these roles imposed, it is possible to argue that the circuses, carnivals, and dime museums provided space in which the anomalous body could assume the 'showman's' subjectivity. In these spaces where deviance was valued the monstrous body was just another anomaly to be deployed in the ongoing saga of relieving rubes of their money. As all workers are exploited when they sell their labour power, so too were the freaks that sold their abnormalities to be gawked at. Of course, many were super-exploited, but within the sideshows they acquired a livelihood, independence, and relative freedom not otherwise available to them. Paradoxically, this freedom may well have been ultimately illusory for the circuses, carnivals, amusement parks, and dime museums provided bounded spaces in which an eye could be kept on the freaks in more ways than one.
However, changing public attitudes towards the anomalous body resulted in the freak show no longer being perceived as a proper form of entertainment but as crude, demeaning, and exploitative. This was hastened with the advent of new, exciting forms of entertainment such as film early this century. The change in attitude is most directly linked to the rise of the medical profession in the latter part of the nineteenth century, and the subsequent redefinition of physical deformity as disease. As such, the anomalous body was transformed from an object of awe to an object of pity to be cured or cared for. This was accompanied with a change in the meaning of the term ‘freak’. Scientific and medicalized terms were now applied to the anomalous body and the term ‘freak’ was increasingly applied to the outsider to signify psychological estrangement, alienation, and marginality. Indeed, as the drug counterculture became entrenched in the 1970s, the Fabulous Furry Freak Brothers, characters of one of the so-called ‘head’ comics of the time, served as an icon for a generation which rejected straight society in favour of ‘freaking out’ on ‘sex and drugs and rock ‘n roll’. To return to the project in hand, the medicalization of the anomalous body and the emergence of disability and the disabled subject within the New Zealand context, are examined in the following chapter.
In the previous chapter it was shown how freaks tended to constitute themselves as showmen rather than their stage personae. Within the circus world they were just another category of entertainers which were regarded in toto by wider society as aberrant and fraudulent. In this sense all circus and amusement world workers, not just the freaks, were constituted negatively by the 'outsiders' in straight society. It, thus, seems perfectly logical for those so constituted to adopt a positive term by which they can commonly identify, such as showmen, in order to counter the negativity of the ascribed term. While this is certainly true of freaks in the amusement world it is only part of the story: from the middle of the nineteenth century the commonplace prejudice which the anomalous body had always been subject to, took new and virulent forms, namely, social Darwinism and eugenics. In these 'scientific' explanations of social development 'the deformed', among others, were cast as part of a degenerate race which was sapping the vitality of society as well as degrading the nation's breeding stock. These theories dominated the debate on social reform that was taking place in Great Britain and the United States of America in the late nineteenth and early twentieth centuries. A debate sparked by taxpayers in the middle and upper classes who saw good money going after bad to support the growing number of 'undeserving' poor, a category of people held to be poor because of their own intemperance. From this perspective, the social reform policies designed to alleviate poverty and destitution were now seen as part of the problem: they encouraged idleness and dependence.

In this chapter, the form that this debate took in Aotearoa/New Zealand will be examined. Attention will be paid to the way this debate shaped the social perception and location of the anomalous body in New Zealand society. This will involve a brief outline of the major tenets of social Darwinism as the prelude to a fuller examination of eugenic thought, its modification, and institutionalization in New Zealand culture via the Plunket Society and Health Camps. The pivotal role played by the Plunket Society in shaping the dominant cultural ideals as to what constitutes 'fit' and 'healthy' bodies will be examined in detail. As the antithesis of these 'able-body' norms, anomalous bodies have been normalized as pathological, routinely made subject to the medical gaze, isolation, institutional care, and created as the disabled.
SOCIAL DARWINISM AND EUGENICS: INTELLECTUAL ORIGINS

Social Darwinism
After Charles Darwin published his evolutionary theory in the Origin of Species (1859), the term 'social Darwinism' was retrospectively applied to the work of English sociologist Herbert Spencer. Almost a decade earlier Spencer had proposed in Social Statics (1850), that both society and biological organisms were subject to the same evolutionary laws (Coser, 1971:90), and that both advanced or developed through the survival of the fittest (Spencer, 1981:109). Spencer's theory of social selection was developed in response to Malthus who had argued that weaklings would always be a part of society; while they would be the first to go under in times of adversity they would continually reconstitute themselves as a class when conditions improved. In contradistinction, Spencer argued that the pressure to survive had placed a premium on skill, intelligence, and the ability to be technologically innovative. Consequently, only the best of each generation were selected for survival and as inferior specimens were weeded out, a cumulatively better race would be produced (Spencer, 1972:34-6).

Malthus (1803), had also predicted that under favourable conditions the population would double every twenty-five years but because checks to increase, that is, vice, misery, and moral restraint (contraception), were operative to varying degrees, doubling would be limited to once every fifty or one hundred years (Chapple, 1907:13). However, almost seventy-five years after Malthus's prophecy a rapid, and what turned out to be continuous, decline in the birth rate of Northern and Western Europe was recorded. This proved to be the undoing of the Malthusian argument; conditions, that is, increases in food production and the purchasing power of people, had never been more favourable (ibid.:17). But what was even more alarming about this decline was that it had a moral component to it as well: the population was not only declining in terms of quantity but also in terms of quality. Both Malthus and Spencer were wrong. According to Spencer, the race would get cumulatively better as the laws of evolution sorted the fittest from the biologically inferior. But this was not happening; the decline was most pronounced in those whose superiority was reflected in economic and social standing, namely, the middle class. At the same time, increases in the birth rate of the

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1 'Social Darwinism' is quite misleading as Spencer was a Lamarckian. He was influenced by the ideas of the French zoologist Jean Lamarck (1744-1829) who postulated the inheritance of acquired characteristics such as poverty or chronic unemployment.
indigent poor was lifting the proportion of degenerates in the overall population: the British race was in a state of decline.

Spencer attributed this moral decline to the impact civilization was having on the natural selection process. He argued that man had thwarted the biological evolutionary laws by enacting social laws which mandated for adequate housing, clean-water systems, effective sewage systems, regulated industry, and succoured the poor through free universal education, and indoor and outdoor relief (Chase, 1977:105). These means stood in opposition to 'the natural order of things [in which] society is constantly excreting its unhealthy, imbecile, slow, vacillating, faithless members' (Spencer cited in Fleming, 1964:125) to leave more room for the deserving. Spencer was particularly adamant that society should not extend state aid to the physically 'unfit'; those who lost out because of weak viscera or malformed limbs should receive no special care because 'if they are not sufficiently complete to live, they die, and it is best they should die' (Spencer cited in Hofstadter, 1959:41). Indeed, the chronic condition of the social organism was directly attributable to a maudlin impulse on the part of the fit to prolong the lives of the unfit. In this process superior specimens are diverted from their proper task of self-realization and propagation of their kind while simultaneously swelling the ranks of marginal people who ultimately became dependent on the state. Spencer's social theory is, above all, motivated by self interest: it represents an attempt to undermine incipient welfare legislation and the attendant increases in taxation by strengthening laissez faire with the imperatives of biology.

**Eugenics**

Writing in 1904, Francis Galton defined eugenics as:

... the study of all the agencies under social control that may improve or impair the racial qualities of future generations either physically or mentally. (Galton cited in Blacker, 1952:109)

Galton's interest in human heredity and variation had been aroused when reading his cousin's (Charles Darwin) *Origin of Species*. In accepting the notion of natural selection, he was prompted to ask why humanity was still beholden to its vicissitudes in this age of science?; surely a programme of rational selection could be developed to improve the species by attending to the production of offspring in a scientific manner? These ideas were developed in *Heredity Genius. An Inquiry into its Laws and Consequences* (1869), and *Inquiries into Human Faculty and its Development* (1883) in which he coined the term 'eugenics' and signalled the birth of eugenic thought proper. However, at this stage eugenics
remained speculative and Galton had to wait until early in the twentieth century before sufficient scientific groundwork had been carried out for eugenics to become a plausible political creed (Searle, 1976:6).

In the intervening period, the modern science of genetics had its inception with the discoveries of the German biologist August Weismann in the late 1880s and the rediscovery of Gregor Mendel's laws of heredity in 1899 (ibid.:60-61). Weismann theorized that the germ cells or germ plasm, which determined what was inherited, were distinct from somatic, or body, cells. Thus, germ plasm could not be affected by changes to the body caused by injury or disease, by use or disuse. This meant that germ plasm passed from one generation to the next unaltered and that the inheritance of acquired characteristics as championed by Lamark, was an impossibility. Eugenists, however, drew further conclusions: environmental changes would be limited, costly, and ongoing. Environmental changes may well reform individual degenerates, but if these people were the way they were as a result of their germ plasm, which was unaffected by the environment, then their progeny would be tainted by heredity and the process of rehabilitation would have to begin anew with each succeeding generation (Fleming, 1981:3). While Mendelian genetics seemed to complicate matters by showing the multifarious interrelations among the genes and between the environment and the way the genes worked when passing on important human traits (Haller, 1984:62), they also contained a solution to the impasse. If Mendelian geneticists could breed 'rustiness' out of wheat it was only a short step away from being able to 'breed out' certain grave hereditary ailments and 'to develop mental or physical qualities in men that were generally regarded as desirable' (Searle, 1976:8).

Thus, unlike the social Darwinists who could only fatalistically await the 'fittest' to displace the 'unfit' as the laws of evolution moved inexorably forward, the eugenists, armed with the genetic theories of Weismann and Mendel, need not stand idly by. Rather, they were, in today's jargon, proactive, proposing a double-edged programme of eugenics: positive eugenics would encourage the 'fit' whose genes carried desired qualities to have more children, while negative eugenics concentrated on restricting the fertility of the 'unfit', who were likely to have defective or undesirable children. And while defining 'who' and 'what' actually constituted the 'fit' was problematic for Major Leonard Darwin, a prominent member of the English eugenics movement, the 'unfit' were unequivocally those:
... many kinds of men that we do not want. These include the criminal, the insane, the imbecile, the feeble in mind, the diseased at birth, the deformed, the deaf, the blind, etc., etc. (Darwin, 1928:25)

These people by way of 'some natural defect of body' were genetically predisposed to 'winning low wages, or failing or not trying to get work of any kind'; if only they 'were to have few children...the result would be a lessening in the future of all natural defects leading to low wages or unemployment' (ibid.:27).

So, buttressed by the discoveries of genetic scientists, the eugenic creed loudly proclaimed those who were disadvantaged as inferior; a blight on the nation that could not be ameliorated by social policy which sought to compensate for structural inequalities. Moreover, social disposition, attitudes, character, were also proclaimed as subject to the laws of heritability; the boundaries between social Darwinism and eugenics were muddied as science became ideology in the hands of men who uncritically used it in the service of their social philosophies. Inferiority in toto is, thus, genetically determined, inscribed onto and immutably locked into specific bodies; the only recourse for eugenists was to breed it out.

Boasting such a clear cut, logical, and apparently scientifically credible programme, the eugenic creed rapidly became the rallying point around which the various currents of Darwinian evolutionism coalesced into a plausible political creed. A process given impetus by Galton's first, and most important, public address in which he outlined his eugenic creed in a paper entitled The possible improvement of the human breed under existing conditions of law and sentiment. This was delivered to the Royal Anthropological Institute, in 1901. He subsequently dedicated the remaining decade of his life (1901-1911) to the formation of the eugenic movement in Britain (see Searle, 1976:9-20; Blacker, 1952:110), defining, refining, and promoting his eugenic creed in numerous speeches and articles in which eugenics was portrayed as a harmonious marriage of science and nature:

Eugenics co-operates with the workings of nature by securing that humanity shall be represented by the fittest races.

He continues, promising:

What nature does blindly, slowly, and ruthlessly, man may do providently, quickly, and kindly. (Galton cited in Pickens, 1968:27)

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2 Today genetic counselling achieves this end. It is supplemented by developments in technology which allow the detection and weeding out of 'inferior' strains of humanity while still in the womb. See below.
In 1904, he funded a research fellowship in national eugenics at University College, London, which became known as the National Eugenics Laboratory and to which he left an endowment in his will. In 1907, the Eugenics Education Society (E.E.S) was formed attracting a sizable membership, noted for its high intellectual calibre. Within two years the E.E.S was sponsoring its own journal, the *Eugenics Review*. At the time of Galton’s death in 1911, the eugenic creed had not only been adopted overwhelmingly by the biological establishment, most leading geneticists, and many in the medical profession in Britain (ibid.:11-12), but was fast becoming a world movement. His ideas were especially influential in the United States with the Eugenics Record Office (1910) on Long Island providing a centre for eugenic research and propaganda. Eugenics organizations were also founded in Germany, Scandinavia, France, Austria, Italy, Japan, South America, and New Zealand. Such was the interest that in 1912 the British E.E.S sponsored a highly publicized International Congress of Eugenics in London. Over eight hundred scientists and social scientists from throughout the world attended (Haller, 1984:17-20).

Having examined the intellectual and scientific presuppositions underpinning the eugenics movement, it is now appropriate to turn attention to the origins, the personnel, and the legacy of the eugenic movement in New Zealand.

**COLONIAL NEW ZEALAND: FERTILE SOIL FOR EUGENIC THOUGHT**

**Antecedents**

By the turn of the twentieth century many of New Zealand’s leading politicians, doctors, and academics subscribed to the eugenic creed (Fleming, 1981:6). This was logical given this group’s prior access to the journals which carried the debates over eugenics, and the predispositions of settler society towards work and relief. Firstly, from the time Britain annexed the colony in 1840, New Zealand had always considered its interests closely aligned with those of the Mother Country. Moreover, England’s problems were seen as New Zealand’s problems and vice versa. In the latter part of the nineteenth century the multiplying hoards of Asia were widely perceived as the greatest threat to the British Empire. This perception, born out of neo-Darwinism, characterized white civilization as being locked in a

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3 The eugenics movement in the United States has been the subject of several excellent books, especially Haller, 1984 (2nd ed) and Kevles, 1985. See also Pickens, 1968 and Chase, 1977.
titanic struggle for survival with barbarians situated lower in the evolutionary scale⁴. Eugenics can thus be seen, at least in part, as a response to these fears insofar as it provided a master plan for confronting the threat from within: the 'unfit'. By improving racial fitness, the nations of the Empire would be assured of victory in their struggle for survival (ibid.:9). The pursuit for racial fitness in New Zealand led to the frequently voiced concern at the country's declining birth rate, the formation in 1907 of the Society for the Promotion of the Health of Women and Children, better known as the Plunket Society, the establishment of Health Camps in 1919 for 'delicate' (unfit?) children, and the campaign for safe maternity, beginning in 1924.

Secondly, settlers had brought with them to New Zealand attitudes about work and welfare moulded by debates over the New Poor Law of 1834 (Tennant, 1989:2) and the prevailing social Darwinism in contemporary British thought (Angus, 1974:18). Hence, the ideals of individualism and self-help were strongly entrenched in New Zealand settlements where the concept of poor relief was repugnant to, and strongly resisted by, settlers who had hopes of a new society free of poverty and want. The Wellington settlement exemplified these attitudes: the poor were generally regarded as being poor as a result of their own laziness, debauched living, and spendthrift character. Hence, there should be no reward for these 'undeserving poor' (Barber and Towers, 1976:19). By 1860, however, most provinces had provision for relief (known as charitable aid from 1870), which was, according to Tennant, 'all too frequently minimal, condemnatory, and grudgingly given' (1989:199). In 1873, the government banned immigrants who were not only a source of physical and moral degeneration but who might become a charge on public or charitable institutions, namely the 'lunatic, idiotic, deaf, dumb, or infirm' (Smith, 1979:20).

As argued earlier, the eugenic creed takes root easily in minds fertilized with Darwinian precepts. Such fertilization began in the colony in the 1870s and 1880s with articles published by two convinced social Darwinists, Dr Duncan MacGregor and Robert Stout. MacGregor, Professor of Mental and Moral Science at Otago University, prophesied the extension of the definition of insanity to include 'hopeless drunkards, hopeless criminals, and hopeless paupers', so that these dangerous classes might be:

⁴ A view restated in a New Zealand Medical Journal, editorial: 'If countries suitable for the white races are not to be fully populated and developed by the white races, it means one of two results, either these countries will be over-run by coloured races, or there will be the most bloody and horrible wars for racial supremacy' (NZMJ, 1922:342).
... made to work for their support, and deprived of liberty until they die, in order to prevent their injuring society either by their crimes or by having children to inherit their curse. (MacGregor, 1876:320)

Stout, Otago politician and former pupil of MacGregor, entered print in the early 1880s with warnings of an emerging class of permanent paupers. Stout, who attributed poverty to individual moral failings, feared that this class of degenerates would pollute the new society (Hamer, 1963:81-3).

Both men eventually occupied positions from which they exerted considerable influence over welfare policy. In 1866, MacGregor was appointed Inspector-General of Hospitals and Charitable Institutions, a position from which he wielded considerable influence over the charitable aid structure in New Zealand, as well as a platform from which he introduced fears about the residuum, and the dangerous classes (Tennant, 1989:43-50). Stout, as Premier between 1884 and 1887 and Chief Justice from 1899, held powerful positions to direct social policy. And, while Stout was later to modify his views on the Spencerian struggle for existence, MacGregor remained steadfast in his views throughout his career (Tennant, 1989:23).

W.A. Chapple: the birth of eugenic thought proper in New Zealand

In 1903 W.A. Chapple, a New Zealand born and bred politician and surgeon, published The Fertility of the Unfit. In it, Chapple advocated negative eugenics as the panacea for the colony's ills. The problem concerned the alarming fall in the birth-rate\(^5\) exacerbated by a decline in the fertility of the 'fit' and proportionately increasing birthrate of the 'unfit'. The solution lay in reversing the situation by encouraging the fit to have more children and by sterilizing the unfit. The book was widely read.

The fit, according to Chapple, were those responsible, hard working, prudent individuals, who were determined to 'support and educate themselves' and make their own way in life without being a burden on the state. All very middle class. The contemporary trend amongst such people, 'the best citizens and the best stock' from whom would issue the 'best progeny' (Chapple, 1903:67), was, however, to limit their fertility in order to achieve their goals in life. This limiting of fertility was having disastrous consequences for the nation and, ipso facto, the Empire.

\(^5\) From 40.8 per thousand in 1880 to 25.6 per thousand in 1900.
Chapple gives an alarmingly wide definition of the racially unfit:

... all those mental and moral and physical defectives who are unable or unwilling to support themselves according to the recognized laws of human society. (emphasis added, ibid.:xii)

Note that when speaking of race, Chapple does not differentiate in terms of Maori and non-Maori settlers, as might be expected in the New Zealand context. Instead, for Chapple, for the eugenist, people are ‘racially’ segregated in terms of (acquired) moral characteristics and physical and mental deficiencies. For Chapple, mental and moral defectives included ‘the criminal, the pauper, the idiot, the imbecile, the lunatic, the drunkard’ (p.xii), while the ‘physical defectives’ were the:

... deaf, dumb, blind, epileptics, paralytics, cripples, debilitated, and deformed. (ibid.:xiv)

What was most threatening about these ‘defectives’ was ‘the fact’ that they were propagating an increasing ‘army’ (p.xii) which would have to be cared for by the taxpayer. The fertility of this ‘army’ was consequent to a stronger than normal ‘sexual instinct’ that was innate to defectives because all were mentally impaired in some way (ibid.:69). Mental impairment and an uncontrollable ‘sexual instinct’ are linked. Consequently, Chapple’s ‘over-sexed’ army includes ‘physical defectives’ as well, because:

... a physical defect such as a club-foot, cleft palate, or any arrested development, is apt to be associated with some mental defect. (ibid.:86)

Having outlined the problem, identified its causes and consequences for the nation and Empire, and determined the unfit to be the main offenders, Chapple goes on to outline the only possible solution: a programme of compulsory sterilization of the unfit.

Chapple, after discussing the possible solutions available - infanticide as practised by the ancient Greeks and Romans, the surgery and lifelong incarceration favoured by Boies, or, most permanently, the method advocated by Dr McKim: ‘the painless extinction of these lives’ which ‘would present no difficulty - in carbonic acid gas we have an agent which would instantaneously fulfil the need’ (ibid.:102) - allows his humanitarianism to get the better of him and comes down on the side of ‘the elimination the unfit by artificial selection’ (ibid.:103), that

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6 Chapple’s assertion reflects the conventional wisdom of the time. That this convention lingers on is borne out by the common experience of the paraplegics I spoke to. They complained that the majority of nondisabled strangers invariably treated them as intellectually disabled.
is, sterilization. Having rejected surgical castration and vasectomy because of the alleged side effects, Chapple recommends tubal-ligature for all defective women of childbearing age and the wives of defective men (ibid.:117). In addition, marriage boards would be established to issue procreation certificates on the basis of a confidential medical report to those intending marriage. If a couple failed, a certificate would be issued upon receipt of a certificate of sterilization (ibid.:120).

Chapple concludes that the future of society demands that compulsory sterilization of the unfit should be adopted, for:

The greater the proportion and fertility of the defective, the less hope for the future. If the fertility of the unfit be reduced to a minimum, not only will many dreadful hereditary diseases be eradicated, but the fertility of the fit will receive a powerful stimulus, because of great diminution there will necessarily be in the burdens they will have to bear. (ibid.:126-7)

Having looked at Chapple's *The Fertility of the Unfit* in some detail, Searle's description of it as 'a hair-raising book' (1976:111) makes sense. Even more 'hair-raising' is the imprimatur given by prominent politicians in letters to the author and reproduced in the book. Chief Justice, Sir Robert Stout, is so impressed he offers to pass the manuscript on to a friend in a large publishing firm in London for publication, and John Findlay, Attorney General and Leader of the Legislative Council in the 1900s, enthuses 'that no finer work on the subject has been accomplished' (Chapple, 1903:iv). It was also well received within feminist circles, with the then president of the National Council of Women, Margaret Sievwright, recommending it to fellow feminist Amey Daldy in 1904 as 'a much needed statement of ugly facts' (Coney 1993:70). The book was widely read. But, no matter how repugnant the treatise is to us today, it is useful to remember that it merely reflects contemporary social

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7 While this was never officially adopted by the New Zealand State, eugenic utopias were sought elsewhere. Especially in America where sixteen states had already legalised the sterilisation of confirmed criminals, idiots, imbeciles and rapists in public institutions (Searle, 1976:94; see also Haller, 1984:130-41). Similar laws were adopted during the 1920s in the Canadian provinces of Alberta and British Columbia, and the Scandinavian countries of Denmark, Sweden, Norway, and Iceland (Haller, 1984:139). In 1933 a programme began in Germany under which about 400,000 people were compulsorily sterilised. The Nazi Euthanasia Programme, the 'silent holocaust', logically followed in 1939. Over 200,000 mental and physical 'defectives' were deemed as 'life not worthy of life' and murdered. Incidentally, the technology for the mass killings in the Jewish holocaust was developed during the adult Euthanasia Programme (Morris, 1991:45-58; see also Lifton, 1987).
philosophy and the concerns of the day, specifically, the continuing dramatic decline in New Zealand's birth rate which had begun in 1880⁹ (see Mein Smith, 1986:8).

In his assessment of Chapple's treatise, Phillip Fleming (1981), says that while it was an important contribution to the eugenic debate within New Zealand, he is unable to gauge with any certainty its influence. He does note, however, that two decades after publication it was still being quoted by doctors being surveyed by the 1924 Committee of Inquiry into Mental Defectives and Sexual Offenders (Fleming, 1981:13). However, from the perspective of a genealogist of the disabled subject in New Zealand, one would venture that such a tract would almost certainly have been used to legitimate the contemporary practice of consigning physically disabled people to the state funded lunatic asylums (see Smith, 1979:20) and the routine sterilization of women institutionalized with intellectual disability⁹. It also marks the 'scientific' confirmation and formal institutionalization of many of the myths, stereotypes, and attitudes which have subsequently dehumanized, excluded, and, in many instances, isolated and demoralized the lives of disabled people in this country for nearly a century.

The eugenics movement in New Zealand

Any assessment of the eugenics movement in New Zealand must focus on the Eugenics Education Society of New Zealand (EESNZ). Its formal records and publications reveal its membership and aims while its public reception and popularity can be gauged from contemporary media comment. The first branch was founded in Dunedin in 1910 by a group of interested people pre-eminently from the medical, clerical, and academic professions. Other branches were quickly established in Wellington, Christchurch, and Timaru. By 1912, membership totalled approximately 200 throughout the country. A relatively small number, but members occupied some of the more powerful and influential positions in the country from where they could disseminate their eugenic creed. For example, the prominent politicians Robert Stout (former Premier and Chief Justice from 1899), John Findlay (Attorney General in the 1900s) and George Fowlds (Minister in Charge of Mental Hospitals) as well as a host of back-benchers; leading academics, including professors of biology Benham, Kirk, Johnson, and Chilton from the Universities of Otago, Victoria, Auckland, and Canterbury

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⁶ This was part of the wider problem which linked the declining birth rate of the British and their white, colonial 'kith and kin' with decline of Empire.

⁹ People who have worked within local institutions for the intellectually handicapped have told me that invariably appendectomy was the code-word for hysterectomy. The frequency of female inmates having their 'appendix out' slowed recently with the deployment of long term contraceptives such as depo prevera.

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respectively; the medical profession was, numerically, the best represented, contributing members from humble practitioners to top health administrators such as W.H. Symes, Chief Health Officer for Christchurch, Truby King the Medical Superintendent of Seacliff Mental Hospital and founder of The Royal New Zealand Society for the Health of Women and Children (later known as the Plunket Society); F. Hay, Inspector-General of Mental Hospitals, and T.B.A. Valentine Inspector-General of Hospitals and Chief Health Officer of New Zealand; teachers etc. from educational circles including O. Flamank, President of the New Zealand Educational Institute, and G. Hogben, the Inspector General of Schools; ministers of religion, keen to take up any cause which would assist the fight against degeneracy and moral decline, formed an important component of the movement (Fleming, 1981:15-24; 73-6).

The eugenic ideal was not, however, an exclusive part of the male preserve; it was widely supported by feminists of the day with some supporting compulsory sterilization. The National Council of Women softened its approach later, tending to prefer farm colonies for 'mental defectives' (Coney, 1993:70).

In gauging the popularity of eugenics, Fleming notes that the EESNZ had become dormant through lack of support by 1914, just four years after its founding. Notwithstanding this, eugenic ideals continued to attract national attention as they were frequently expressed in the following decades in debates over a variety of issues - venereal diseases, incipient mental illness, sexual crime, the plight of the feeble-minded (Fleming, 1981:84), and the campaign for safe maternity (Mein Smith, 1986:23-40). Fleming also interprets the lack of correspondence on eugenic issues in contemporary newspapers, despite extreme comments from some eugenists and editorial comment which generally accepted that the procreation of the unfit was a problem, as a sign of public disinterest (Fleming, 1981:72).

Public disinterest, maybe, political disinterest, no. Amongst the recommendations of the Committee of Inquiry into Mental Defectives and Sexual Offenders 1925, was the establishment of a Eugenics Board and the segregation and sterilization of mental defectives (AJHR, 1925, H-31A:5,8,23). And while the government stopped short of compulsory sterilization in the Mental Defectives Amendment Act 1928, it was strongly criticized by committed eugenists, including prominent members of the Women's Division of the Farmers Union, notably Dr Doris Gordon and Dominion Vice-President Nina Barrer (Coney, 1993:71). Notwithstanding, a special board was established under the Act to compile a register of all 'mental defectives' and to oversee their care and attention. While apparently rejecting the
more extreme recommendations of the 1925 Committee, a closer examination of subsequent legislation governing disability and disabled people in New Zealand reveals that much of it is underpinned by eugenic ideals. This heritage is most obvious in legislation prior to the 1950s, but still present in that of the 1970s (see below). Fleming, although he might not have had these particular outcomes in mind, does conclude that the effects of eugenic thought in New Zealand have been far reaching:

The real significance of eugenics ... lies ... in everyday terms which are difficult to assess. Through its influence on school medical officers, doctors, and social workers, many of whom displayed eugenic attitudes ... the eugenic creed and all that it implies inevitably touched the lives of many New Zealanders. (Fleming, 1981:83-4)

TOUCHING THE LIVES OF ALL NEW ZEALANDERS: ENVIRONMENTAL EUGENICS

Some of the ways in which the eugenic creed ‘touched’ (and still touches) the lives of many New Zealanders with disability have already been articulated. Of considerable interest is what lasting effects, if any, has the eugenic creed had on shaping non-disabled New Zealanders’ perceptions of and attitudes towards their bodies personally and the body in general? Did the aim of producing better ‘stock’ through scientific breeding disappear without trace following the demise of the EESNZ in 1914?; or were eugenic principles repackaged, cloaked in different language and pursued by other means? No and yes. Succeeding governments had pursued pro-natalist policies of positive eugenics, exhorting, especially, members of the middle class to procreate. Added weight was leant to these policies by the medical profession which roundly condemned the increasing use of artificial contraception by the middle classes to limit the size of their families (see New Zealand Medical Journal, 1922:341-2; Riley, 1930:144-52). Negative eugenics, the enforced sterilization of non-disabled criminal elements, idlers, and loafers, had never really been a viable option in New Zealand. However, another strand of eugenic thought, which came to be known as

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10 Information on birth control was very difficult to obtain at the turn of the century. In 1924 the Customs Department refused to allow Stopes’ book on contraception, Married Love, into the country on the grounds that it was an ‘indecent document’ (Brookes, 1986:123). The Sex, Hygiene and Birth Regulation Society (1934) - later, The New Zealand Family Planning Association, (NZFPA) - founded by Elsie Locke to provide the reliable information on birth control which was not forthcoming from doctors, was strongly opposed by the medical profession. New Zealand women had to wait until 1953 when the Association opened the first birth control clinic. Opposition from the medical profession did not abate however, with the Ethical Committee of the Medical Association publishing a statement in 1960 warning against ‘lay societies’ i.e. the NZFPA meddling in ‘medical matters’ (Fenwick, 1980:86).
'environmental eugenics', was far more palatable politically. This theory down-played hereditarian explanations of indigence, criminality etc and sought explanations in the physical and moral environment. It is of interest that while the 'genetic' line dominated debates in Europe and America, environmental theories featured more strongly in eugenic circles in Australia and New Zealand (Mein-Smith, 1986:24). Perhaps this reflected the newness of Antipodean societies where the possibilities for creating new societal infrastructures were much greater; of weeding out inferior strains while improving the environment at the same time (see Gurr, 1928:123). In New Zealand Truby King was a vociferous proponent of environmental eugenics. He used the Plunket Society, which he founded in 1907, and later his position as Director of Child Welfare to disseminate his ideas on the bearing and rearing of children with the expressed aim of producing healthy and moral adults. The subsequent discourse on 'mothercraft' which he built and proselytized throughout the country was little more than a modified and repackaged version of the eugenic creed; a strict protocol of infant care couched in terms of 'patriotic duty' which the mothers (and fathers) of New Zealand had to follow if Nation and Empire were to survive. Of particular interest is the way King articulated character and body, his thesis being that to build healthy bodies was to build healthy minds, that disciplined, regulated bodies produce moral, normalized citizens.

**Truby King: from Seacliff Asylum to Plunket Society**

Dr Frederic Truby King was appointed Medical Superintendent of Seacliff Asylum in 1889, a position he held for thirty years. The position also included the Lectureship on Psychology and Mental Diseases at the University of Otago - a position which kept him well versed in current debates on 'racial fitness'. And although he became a member of the Wellington council of the Eugenics Education Society, he was a somewhat ambivalent eugenist, critical of the scientific basis of the principles being espoused. In 1906, he published:

> ... the world has come to centre too much attention upon ... heredity ... regarding it as an absolutely dominating factor which must, of necessity, determine ... bodily and mental tendencies.... tendencies are inherited, but observant and thinking men are coming to recognise ... that hereditary tendencies can be overcome by environment ... and can always be greatly modified by suitable conditions of life and training.... (cited in King, 1948:156)

11 King's slogan 'Perfect motherhood is perfect patriotism' was adopted by the Health Department in its campaign for safe maternity in 1924 (Mein Smith, 1986:23).
And while he strongly disapproved of the procreation of certain categories of the ‘unfit’, King continued to dispute the contemporary scientific canon that ‘unfitness’ was passed on genetically. Rather, he promoted his belief that ‘unfitness’ was more a matter of getting it wrong from the moment of birth. Getting it wrong in terms of modern society’s move away from nature, the poor nutrition of infants, faulty rearing, and the lack of relevant education in later life. It was, according to King, these social and environmental factors which produced the weaklings of society: physical and moral degenerates, the insane. Deeply concerned about this perceived fall-off in racial fitness coupled with a high rate of maternal and infant mortality, he declared in 1905 that:

If women in general were rendered more fit for maternity, if instrumental deliveries were obviated as far as possible, if infants were nourished by their mothers and if boys and girls were given a rational education, the main supply of population for our asylums, hospitals, benevolent institutions, goals and slums would be cut off at the source....

More importantly, it followed that:

... a great improvement would take place in the physical, mental and moral condition of the whole community. (King cited in King, 1948:84)

This passage reflects King’s belief that character, psychology, disposition, cannot be separated from the body, a belief he put into practice during his residency at Seacliff. Here he introduced a programme of natural and physical rehabilitation centring on the body: improved nutrition, productive physical work in the natural environment (Seacliff was a farm asylum), outdoor pursuits in the extensive gardens he had developed. His method is captured succinctly by his biographer:

12 Indeed, King was a member of the Committee of Inquiry into Mental Defectives and Sexual Offenders (1925) which included in its recommendations the establishment of an official Eugenics Board, the compulsory registration of mental defectives who would be prohibited from marrying, and the sterilisation of people with incurable congenital mental disorders.

13 King’s strong advocacy for natural child birth (he strongly opposed forceps delivery) and for a return to breast feeding, ‘nature’s nutrition’, was consistent with the neo-Darwinism and romanticized naturalism underpinning eugenic arguments (see Pickens, 1968:3-22).

14 King’s belief in ‘natural treatments’ is reflected in his later rejection of the wide use of drugs, psycho-analysis, and psychotherapy in treating the mentally ill (Caldwell, 1984:39).
when he found a patient who had absolutely no wish to do anything, he would concentrate on the body with the hope that the mind would eventually respond. (ibid.:90)

Very portentous. At Seacliff Truby King’s ‘body-work’ was aimed at cure, at retrieving rationality. Justified by a universalistic and naturalistic view of the ‘British’ subject, it was just a short step away from prevention, from reversing the trend towards degeneracy, from ‘mothercraft’, from The Society for the Health of Women and Children and the widespread production of ‘Truby King babies’.

**Mothercraft technique: normalizing bodies, normalized New Zealanders**

It is the protocol, the techniques of mothercraft which shaped pakeha New Zealander’s attitudes and perceptions of body and self in such profound manner which are most pertinent. The immediate aim of the Society was to train women to see themselves and their bodies in specific light, to inculcate the ‘responsibilities of maternity and the duty of every mother to fit herself for the perfect fulfilment of the natural calls of motherhood, both before and after child-birth’ (reprinted in King, 1948:154). In other words, to instill middle-class perceptions of the female body, middle-class values of motherhood, family, and home life (especially in the working classes where moral, mental, and physical degeneracy was believed to be concentrated). This inculcation should begin at puberty (just as maternal instincts were beginning to assert!) via a state sponsored education curriculum which focused on training girls’ bodies in ‘domestic management, domestic economy, physiology, and hygiene’ (Batchelor, 1909:7). Ideally, corporeal education would continue seamlessly with girls entering domestic service, honing skills that would eventually make each ‘a better wife and mother, and ...more likely to rear ...healthy stock’ (ibid.:6).

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15 It would be erroneous to conceive King as some kind of humanitarian maverick in his treatment of the insane. While his techniques were certainly in advance of popular opinion, Cardwell (1984:62) notes that they were in keeping with the biological and organic theories of contemporary academic psychiatry.

16 The vehicle for spreading the protocol began as the Truby King Mothercraft Society (1905), was renamed The Royal New Zealand Society for the Health of Women and Children in 1907 and eventually became commonly known as the Plunket Society following the active patronage of the then Governor’s wife, Lady Plunket. See Truby King - the Man, by his daughter, Mary King (1948), for a somewhat narrow focus on the early years of the Society. For more detailed, but largely descriptive histories, see Milne, 1976 and Parry, 1982; Olssen, 1981, provides a critical analysis.

17 At a time when girls were increasingly reluctant to become ‘domestics’, Dr Batchelor’s address to the annual meeting of the Plunket Society must have been music to members’ ears who, in the early years, were almost exclusively upper-middle class ladies (Milne, 1976:51).
Mothercraft for the expectant mother consists of regular habits and detailed bodily surveillance and maintenance. Since the ongoing advance of civilization and national efficiency depends ultimately on teeth (King, 1951:77), dental care is prioritized; diet should be simple, nutritious, sufficient. Very hot baths are to be avoided: cold bathing followed by a brisk rub with a rough towel is highly beneficial, integral to the general bracing and toning up of the pregnant body. True motherhood, normal motherhood, natural mothering, depends upon the breast, on feeding Baby with mother's own milk: a detailed regimen of daily care is prescribed with particular attention being paid to the nipples which must be 'formed' and toughened. But, a note of warning, the nipples should not be stimulated to excess: moderation in all things! Mothercraft is always as much about self-discipline and self-regulation, the moral control of women, as it is about care of Baby. Above all, the prospective mother must keep herself physically fit and active: a regular daily walk, in all weather, fresh air, sunshine, exposure to the elements: natural being, natural mothering. She must not become idle, self-indulgent, regard herself as 'half an invalid', sink into lazy inactivity: this is 'the worst kind of mother' who generally has a 'bad time all round' (ibid.:52). Nothing is left to chance. The outer body must be suitably heeled ('thick soled, low-heeled, sensible shoes') and clad lightly rather than heavily. Inwardly, the expectant mother must never be depressed if she is to produce 'a happy, cheerful, and contented baby' (King 1941:21); equally as important is training the bowels to move with regularity and ease each day: constipation made the blood 'impure and poisoned', seriously weakening the unborn child (King, 1951:51-7). A normalized expectant mother is created and recreated in King's regime of body maintenance, an archetype for the comparison and measurement of pregnant bodies, a discipline to which all pregnant women must scrupulously adhere, for:

... the physical destiny of her child is in her own hands, to make or to mar.
Bodily fitness largely determines mental and moral capacity ... success as well as the happiness of life. (ibid.:50)

As Olssen notes, 'Expectant mothers, if they took King seriously, must have had ample cause for guilt' (1981:14).

Mothering, the deployment of mothercraft, acquires added complexity, demands extra vigilance with the arrival of Baby. It involves precise techniques of bodily care aimed at the formation of character as much as the survival of the infant. In the process, time, a measured, hierachized temporality is stamped on both Baby and mother's bodies; the clock determines when and how baby sleeps, is fed, moves its bowels, is washed, clothed,
exercised, mentally stimulated, exposed to fresh air and sunshine, mothered, and managed (King, 1951:82-131).

Another aspect of the body, that of normal, physiological function underpins the regimes surrounding the breasts and breast feeding. Breast feeding, the provision of 'the only perfect food' 'pure, fresh, living' 'Natural milk drawn ...direct from the mother's breast' is elevated to the sacramental expression of mothercraft. Breast feeding, the core activity of natural mothering (true mothering) marks out the genuine, normalized, 'Truby King' baby from the rest. Damningly, King warns mothers engaging in 'unnatural' mothering that when her child learns what the most important factor in its development was, the child will probably ask:

"Did you give me the milk the good God gives with every mother, or did you rob me of my birthright?" (ibid.:50)

Seen in this light, breast feeding is next to Godliness. It is the specific deployment of body through which the true woman experiences her essential, natural being, feels most complete, fulfils her ontological vocation as mother. Nature, however, could not be left on her own to do her duty correctly for breast feeding is as much about the formation of character as it is about nutrition. Mother must discipline her body to produce a nutritious and adequate supply of breast milk. The best way to ensure this is for 'mother to lead a bright, happy, active home life' (ibid.:63) coupled with the continuation of the discipline of bodily maintenance begun during pregnancy. In addition, particular attention is now paid to keeping the breasts in a sound state of repair, measuring, testing and ensuring adequate milk flow (King, 1941:55-85). Breast feeding, the cosmic, corporeal conjunction of mother and baby, builds sounder and healthier mothers and children. So, to be a complete mother, to be a complete woman, requires a complete and fully functioning body. Also, since there is something profoundly moral about breast feeding and the physiologically functioning breast, the notion of wholeness of character and self is intimately linked to wholeness of body and physiological function.

Training women in breast feeding, the preparation and use of humanized milk and certain principles of domestic hygiene - these were the sorts of messages the Plunket Society concentrated its energies on spreading during its first twenty years. Dissemination begun early with the Kings (Truby and wife Isabella) publishing a weekly newspaper column, 'Our Babies', under the pseudonym 'Hygieia'. By 1913, it appeared in over fifty newspapers reaching into practically every home in the country (Olssen, 1981:11). It contained articles from breast feeding to adenoids, house flies to weaning, castor oil, diet, weighing,
constipation, precocious children, and a section in which readers' questions were answered (Parry, 1982:48). A series of books followed in which King elaborated the craft of mothering: *Feeding and Care of Baby* (20,000 copies sold in five years, first British edition published in 1913); the Government commissioned *Baby's First Months*, printing 30,000 copies and issuing all mothers a copy within a few days of childbirth. Macmillans published an enlarged and revised edition, *The Expectant Mother and Baby's First Months*, in 1916, which the New Zealand Government reprinted and issued a copy to all marriage licence applicants (Olssen, 1981:11). This was updated by the society's medical advisor, Dr Helen Deem, in 1945. Published as *Modern Mothercraft*, it had sold 40,000 copies within three years (Coney, 1993:65).

The practical basis of the word was located in the Karitane Home for Babies in Andersons Bay near Dunedin. King had founded this home in 1907 as a place where mothers with sickly babies could learn the essentials of mothercraft. Within twenty years, nurses were being trained in Plunket methods at six Karitane Hospitals around New Zealand (ibid.:64).

The message was spreading, being heeded\(^\text{18}\), and effecting dramatic results: infant deaths in Dunedin had dropped from twenty-five per 1000 in 1907 to four per 1000 in 1912, to less than one per 1000 in 1917 (M.King, 1948:155); across the country infant mortality dropped\(^\text{19}\) as word spread. While King and Plunket were keen to accept full responsibility for this good news, the effects of the provisions within the Public Health Act 1890 on infant mortality and infant morbidity cannot be ignored. Under this Act a new emphasis was placed on environmental health and the provision of sewage and drainage systems, clean drinking water, and food and habitation hygiene in the larger towns (McLean, 1964:19).

\(^{18}\) The timing and social context in which King delivered his message offers a compelling explanation for the wholesale adoption of Plunket ideology. Social Darwinism and eugenic thought provided the intellectual background while mothercraft meshed nicely with the cults of domesticity and true womanhood that flourished from 1880 to the 1920s in response to the changing role of women in a period of rapid urbanization (Olssen and Levesque, 1978:6-12). Increasing numbers of girls were going onto secondary and technical schools to obtain job qualifications, more women than ever were attending University and entering the professions (Hughes, 1980; Page, 1992), and still more were entering the work-force generally (Olssen, 1980). Moreover, many feminists of the time were advocating compulsory domestic training to prepare girls for marriage and economic independence (Coney, 1993:202). The imperative for racial fitness, following the alarming revelations of the medical examinations of recruits for the Boer and First World Wars (Mein Smith, 1986:3-4), and a declining birth rate coupled with high levels of infant and maternal mortality added urgency to King's message. The message struck a chord, the technique spread rapidly with sixty-five per cent of all non-Maori infants under the care and control of the Society by 1930, eighty-five percent by 1947 (Olssen, 1981:11), rising to ninety percent of all babies born in 1992 (Coney, 1993:66).

\(^{19}\) To a rate of forty per 1,000 live births by 1928 (Parry, 1982:80)
When King was appointed the first Director of Child Welfare in 1921, Plunket ideology officially became Government policy. State resources were subsequently deployed in a programme of environmental eugenics aimed at increasing national efficiency, producing fit and healthy stock, by encouraging higher standards of motherhood via techniques of mothercraft. By 1924, King was able to declare that together the Plunket Society and Government had gone 'a long way towards ensuring uniform, authoritative advice in regard to matters bearing on family life, and the rearing and treatment of children in health and disease' (King cited in Olssen, 1981:13). Having established the norm and normalized bodies, the Plunket Society turned its attention to normalizing the character structure of the Nation's stock.

**Regularizing bodily functions - building character structure**

At the heart of character formation is the inculcation of a 'regularity of all habits' underpinned by the discipline of the clock. Mother must follow a prescribed programme of regular, four hourly feeding with an eight hour break at night. She must not over-feed or under-feed, must encourage vigourous sucking (prolonged suckling gets the baby into the bad habit of dawdling!), weigh Baby before and after each feed, measure its length weekly, ensure its bowels move daily precisely after the ten a.m. feed (King, 1913:62).

The 'when' of bowel movement is most crucial for it is over this bodily function that baby exercises most sovereignty. Baby must therefore bend to the will of mother, discipline its self and body to respond to external authority, know and experience its body appropriately. Successful resistance to this mode of character formation was manifested corporeally as constipation. King was obsessed with constipation (ibid.:9, 109-13) for it had dire moral consequences. In boys the long term effects of constipation were masturbation, a most damaging form of self-indulgence which 'interferes with proper cerebral evolution' altering the character structure of the individual irrevocably (ibid.:150).

Without the correct management the child, King warns, will be 'spoiled', transmuted into, 'a source of anxiety and worry ...[a] cross, fretful ...exactiing little tyrant' (ibid.:98). Equally, mother must not break established patterns, weaken and succumb to cries for food between feeds. If she does she risks 'spoiling' the child by encouraging its indulgent and self-seeking tendencies. Such infants grow into the adult idlers who clog the gaols, slums, and

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20 The notion of 'regularity' of body and mind is important to this thesis not only because of the premium society places on regularity per se, but also because the paralysed body is anything but 'regular', especially in terms of bodily function over which the subject has no control. A fuller discussion of these aspects follows in Part Two.
benevolent institutions at great moral and economic cost to society. A regime of regularity of all habits is, thus, central to developing both physical strength and moral character; patterns of self-discipline, self-control, self-reliance in later life are inscribed upon the infant's body and into her/his psyche now - the most crucial time in its development as a moral being - by the regular and precise ministration of normalizing management and mothercraft technique.

Mothercraft parallels the techniques of bone manipulation and infant swaddling, as prescribed by the Renaissance physicians (see above), insofar as both are techniques applied directly to the infant's body in order to produce certain effects. King's bodily technique does, however, differ in terms of target population and stated outcomes. First, it is prescribed for the entire population, not just a particular class. Second, it is about actually producing a particular character whereas courtiers demanded of their physicians bodies which simulated character. Then it was held that the soul chose a body to reflect its character, so it was a prudent investment to manipulate the infant body so it might display the desired character in adulthood. Ultimately then, courtier corporeality simulates and dissembles as opposed to the truth of the 'Truby King baby', the body upon which mothercraft plays in order to produce strength of character and to ensure the physical and moral regeneration of the Nation.

The bourgeois idealization of home, hearth, and family are endlessly exhorted in Plunket propaganda as the environment in which the effects of the technique are maximized. In short, mothercraft is as much a technique of middle class hegemony as it is about the care of women and children (see Olssen, 1979a:19). A bio-politics which simultaneously inscribes norms for the measurement of health and fitness on individual bodies, and bourgeois values and predilections on the body-social; prescriptive norms of mothering, technique, corporeality and character structure which constitute and coalesce in a new national icon - the Truby King baby.

The Truby King baby: icon, iconology, and surveillance

A discourse involving the norms of corporeality, technique, measurement and judgement quickly grew up around Truby King's notion of the physically fit infant. The parameters were set in his newspaper column, modified, added to, refined in his various publications and through the practices of the Plunket Society. In effect, this amounted to a comprehensive surveillance infrastructure which subjected the mothers and infants of the nation to continual scrutiny both from within and without. The literature provided the material for self-surveillance in private, and for comparative purposes in public. The numerous branches and sub-
branches of the Society that sprung up throughout the country were the institutional settings for further comparison, ranking, and surveillance. Indeed, a kind of hysteria gripped the country as to what constituted the 'true Plunket Baby' (read Truby King baby). Gordon Parry quotes a woman writing to Hygeria arguing that the use of humanized milk, while necessary, was not sufficient:

One baby, supposed to be of the Plunket persuasion, begins its meals at 3.30 a.m., with the next following at 6 a.m. and another at 8 a.m. I don't know how many are crowded into the day. This baby also has a dummy and the day I saw him was covered so thickly with shawls and wrappings ... has a spotted face and sleeps in a small servant's room with an entirely untrained foolish nursemaid. (Parry, 1982:75)

Obviously further policing was needed. This arrived in 1924 in the form of the Plunket Book. Issued to all mothers, it contained a weight chart, room for mother to record baby's progress or lack of progress, and space for the Plunket nurse to record her observations and suggestions about feeding and care. That it arrived with King's elevation to Director of Child Welfare, and the growing intolerance of the Society to any who deviated from the rules, seems more than mere coincidence. According to Olssen, the Society, by this time, was 'convinced of their monopoly over knowledge ...its fast-growing cadre of nurses ...imposing the conception of ideal character' (Olssen, 1979b:21). One can imagine mothers, nervously awaiting the Plunket nurse's visit, the measuring and weighing of baby, the entering of record. She was on trial, her mothering being judged and recorded for posterity. So was baby. Did it conform to the norm? Was it normal, a normalized baby? The Plunket Book was the ultimate in surveillance technology.

With the publication of Mothercraft by King's daughter, Mary, in 1934, the creation of a national corporeal icon was completed, and cemented in place. In the opening chapter, she details the corporal and emotional attributes of a 'real' Truby King baby, who:

[is] not too fat - every bit of his flesh is firm and clear. His eyes are bright, and one has only to hold him for a moment to appreciate his muscular tone. He is not a ... plaything, made to laugh and crow and 'show off' to every visitor... yet he is the happiest thing alive, gambolling with his natural playthings, his own hands and toes; ... he is a joy from morning till night to himself and all the household - a perfectly happy and beautiful 'real Truby King baby'. (King, 1941:4-5)

\[21\] By 1928 the Society had sixty-four branches with Plunket Nurses and 500 sub-branches which were visited regularly by the nurse. In that year 500,000 visits were made to Plunket Rooms by mothers and babies while nurses made over 180,000 home visits (Parry, 1982:80).
For good measure, a photograph of an icon, Shirley McKillip, a prime Truby King baby, is included. This continues the tradition of display, comparative measurement, judging and ranking of babies that began in 1907 as part of the New Zealand International Exhibition. The Exhibition Baby Show marked the beginning of a peculiar form of iconology destined to become intrinsic to New Zealand culture until the late 1960s, when, in keeping with the pop culture of time, the fashion of showing babies began to decline. This was a culture characterized by a rejection of middle class mores, the adoption of more relaxed approaches to child rearing and discipline, and an abhorrence of all types of conformity.

Notwithstanding these changes, a half a century of lived Plunket ideology cannot be swept aside; a mode of living in which a national icon - the Truby King baby - had been created and the corporeal stratum established on which to build a nation of sound health and sound character22. But, an important element is left out of the Plunket equation - the question of the anomalous body, the anti-icon, disability, and the disabled subject. How was this anti-icon perceived? What happened to this antithesis? What was to be done with this corporeal unseemliness and, by implication, moral impropriety? First person answers to these questions are not readily available, but a register of the social services provided for 'mental and physical defectives'3 does exist. From this register, that is, the legislation directed at regulating anomalous bodies, answers can be mined.

REGULATING THE ANOMALOUS BODY IN AOTEAROA/NEW ZEALAND

In 1898, Dr Duncan MacGregor, the Inspector of Hospitals and Charitable Institutions, reiterated the view in his annual report on hospitals and charitable aid that society was in decline. A true Spencerian, MacGregor was concerned that the charitable aid system was actually facilitating this degeneration of society by 'subsidising the survival of the unfit'

22 Indeed, it is interesting to note that it is the Plunket babies of yesterday who as the adults of today are into bodywork in a big way, the discipline of the health and fitness centres, the fanatical, and very public, pursuit of the new icon: the body beautiful, the encapsulation of today's most sought after moral and character traits (see Chapter II).

23 Given the contemporary conditions of knowledge it is appropriate to subsume both mentally and physically disabled people under the rubric 'anomalous body'. There was a melding of conditions with certain categories of physically anomalous bodies (eg deaf mutes, cerebral palsied, 'the crippled and deformed') being abandoned in the state lunatic asylums where they could be cared for. This practice was sanctioned, and undoubtedly encouraged, by the Lunatics Act 1868 which defines a lunatic as 'any person ... incapable of managing himself or his affairs and whether found lunatic by inquisition or not'.
While impossible to stop, it was possible to ‘retard’ the process ‘by secluding degenerates from the possibility of procreation’ (ibid.). This recommendation added impetus to the policy direction already under way, a policy of separation that is most discernable in the care of anomalous bodies and their ongoing medicalization in the hospital setting, the developing education policy where segregation masquerades as the provision of ‘appropriate’, specialized services in especially designated space, and the semi-institutionalized ‘homes’ that allow groups of physically disabled people to live ‘in’ the community.

**Medicalizing anomalies**

From 1841, the physically anomalous body, along with other ‘incurables’ has been largely segregated and cared for in hospitals, charitable benevolent institutions and lunatic asylums scattered throughout Aotearoa/New Zealand (see Smith, 1979:20). This process was formalized in 1908 when MacGregor’s successor, Dr Thomas Valintine, announced that the incurably ill would be sent to the old peoples’ homes where separate chronics’ or incurables’ wards would be constructed, if necessary. For years, the hospitals and benevolent institutions had been squabbling over who should care for these long stay, non-fee-paying patients. Valintine reasoned that the stigma of having them placed in charitable institutions might prompt family responsibility for these cases (Tennant, 1989:170). In 1910, the inevitable was realized when the hospital and charitable aids boards were amalgamated: the old peoples’ homes with their ‘chronics’ wards became convenient dumping grounds for the physically anomalous body, repositories, in which physically disabled people of all ages languished alongside decrepit and dying bodies (see Tennant, 1983:18). At the same time, the link between disability and charity, disability and dependence, disability and disease, disability and decay, was forged ever stronger.

With the outbreak of the First World War, greater emphasis was placed on the old peoples’ homes’ medical capabilities as they were transformed into secondary hospitals (ibid.:171), centres of care and rehabilitation for the returning causalities, the dis-abled soldiers. Doctors too, returned from the front equipped with new surgical, preventive and corrective skills developed during the course of the war. Orthopaedics, the branch of medicine dealing with the correction of deformities of bones or muscles, had advanced markedly and, not

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24 This continues the process beginning at the turn of the century and prompted by advances in medical science: the curative hospital and the professionalization and specialisation of services (see Smith, 1979:20-23).
surprisingly, doctors were eager to apply these new techniques to civilians in need. Special wards, segregated space, were set aside in the public hospitals (Wards 14 in Wellington and Christchurch Public Hospitals) for the long term rehabilitation of polio 'victims'. In Auckland, the Wilson Home for Crippled Children and, in Wanganui the Duncan Hospital for Neuromuscular Disease, were private, charitable spaces where young polio victims could be treated. Thus, 'the paralytic', 'the cripple', 'the deformed', the monsters and freaks of the previous chapter, were increasingly subjected to the medical gaze, diagnosed with greater precision, sorted into various medical categories, and, for the sake of convenience, became known quite simply as the disabled. More importantly, disabled people became subject to the curative regimes of the hospital, and the medical profession, and disability became synonymous with pathology and disease requiring medical intervention. In short, disability had become medicalized.

Cumulative advances in diagnostic and surgical technique, physiotherapy, rehabilitation methodology, palliative drug therapy, and technology, continued to increase the survival rate of anomalous bodies as well as prolonging and enhancing their quality of life. Prompted by the former, and facilitating the latter, multifarious professionals evolved to divide and then police the various aspects of the anomalous body. Psychologists, to ease minds into their devalued bodies; physiotherapists, to restore movement; occupational therapists (OTs) to enhance productivity; speech therapists to improve communication; orthotists to design, construct and fit splints and callipers; technologists to develop aids and appliances to extend function; rehabilitation experts to coordinate the training of the anomalous body in the art of

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25 Those, mostly children, left with some degree of paralysis following the poliomyelitis epidemics of 1916 and 1925, were the most obvious targets. The epidemics of 1937, 1947-49, 1952-53, 1955-56 provided more cases for the application and refinement of orthopaedic skills. Reconstructive surgery involving the stretching or transplantation of tendons to correct 'drooping foot', was most commonly deployed. Corrective surgery involving the implantation of Harrington rods to support twisted spines and bone grafting to facilitate movement was used to a far lesser extent. Despite these heroic interventions, from 1937 the most productive treatment was that carried out by physiotherapists. This treatment, known as the Kenny method, consisted of applying hot packs and passive movements to paralysed limbs to prevent deformity caused by muscle shrinkage and wastage (Butterworth, 1994:58-65).

26 1913, School of Massage established in Dunedin; Masseurs Registration Act 1920 provided for the registration and training of masseurs, later referred to as physiotherapists (PTs); the Physiotherapy Act 1949 covers registration and training of PTs (see Anderson, 1977 on Physiotherapy in NZ).

27 Many attempts to establish occupational therapy (OT) units in mostly mental hospitals had been made up until 1940 when the first training school for OTs was established at Auckland Mental Hospital; the Occupational Therapy Act 1949 provided for a statutory board to oversee the training and registration of OTs (for an account of OT in New Zealand, see Skilton, 1981).
survival outside the hospital, clinic, or unit; social workers to facilitate access to accommodation, welfare benefits, and services in the outside world.

**Voluntary control of anomalies**

In 1935 the Crippled Children's Society (CCS) was born out of orthopaedic surgeons' frustration (especially A. Gillies) with the lack of services for polio victims who could not afford hospital care or for those already discharged from hospital. With the backing of Rotary Clubs, a national appeal was launched. Branches were subsequently established around the country, becoming the mainstay of home support for disabled people and their families. CCS provided a variety of services including travelling clinics, aids and appliances, transportation to clinics, educational and vocational training (the CCS operated an extensive network of sheltered workshops), advice, and financial help. With the passing of the Disabled Persons Community Welfare Act 1975, the state accepted responsibility for the provision of these services, acknowledging that the voluntarism of the CCS could not cope with the demand (for an account of the first twenty-five years of CCS, see Carey, 1961). This did not, however, signal the end of CCS. It still provides a variety of services and it still has a highly publicised annual appeal.

While not discounting the realities of physical disability and the crucial support CCS provided during the forty-year interim, the assistance was double edged. First, CCS operated from a highly medicalized account of disability and, second, it shamelessly promoted images of crippled, dependent child-waifs in annual appeals for charity donations. It was presumed that disabled people would be grateful, passive, compliant in exchange. A particular perception of disability, disabled people, appropriate behaviour toward them, and what to expect in return was, thus, generated by CCS as a survival technique for the organization. It became the dominant perception, a perception upon which many other voluntary organizations for 'the disabled' were to trade. From this perspective, CCS was a central part of the carceral archipelago that was being assembled to control and regulate the physically anomalous body in New Zealand; a controlling hand in the velvet glove of paternalism, voluntarism, and

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It was not until the mid-1950s that the Department of Health took on responsibility for medical social work. Prior to this voluntary agencies such as the Red Cross and the Crippled Children's Society had been active in this area. New Zealand's first School of Social Work was established at Victoria University College in 1949. The first intake of students was in 1950. This was followed by an increasing interest in the professionalization of social welfare services in the 1960s. The State Services Commission established in service training at Tiromoana in Porirua in 1963, at Levin in 1970, and at Taranaki House in Auckland in 1974. In 1975 Massey University offers a Bachelor of Social Work to young school leavers and extramural candidates (see Anderson, 1972; Elworthy, 1986).
charity. Meanwhile, the state, operating in tandem with the voluntary sector, provided institutional arrangements for education and accommodation which effectively segregated many physically disabled people from the mainstream.

**Special education and people with physical and sensory disability**

The policy recommendation of seclusion by MacGregor in 1898, was an endorsement of moves already afoot in the area of education, specifically the education of the blind and the deaf and dumb. The Sumner Institute for the Deaf and Dumb, the world's first government funded residential school for the training of deaf mutes, had opened in 1880. This was followed in 1890 with the Jubilee Institute for the Blind opening in Auckland. The Institute was a residential home built and maintained by private interests using public monies (Mitchell & Mitchell, 1985:7-10). With these spaces available, the precedent was set for removing children from their families for special residential education. As remedial skills more medically based than lip reading and braille developed, the precedent was progressively applied to children with other disabilities.

A series of amendments to the Education Act 1877 formalized the procedures. Clause 15 of the Education Act Amendment Act 1907 provided for the compulsory education of 'defective or epileptic children', between the ages of six and 21 years in special schools or classes. In the Education Amendment Act 1910 a defective child was defined as someone who by reason of mental or physical defect could not benefit from ordinary schooling. Power was given to the Minister to direct blind, deaf, feeble-minded, or epileptic children to the relevant institution or 'special school' for education if their parents were not providing 'efficient and suitable education'. The Education Act 1914 made it obligatory on parents, and a variety of officials including teachers and police constables, to report any mentally defective children to the Department of Education so that arrangements could be made for their appropriate education (clause 129). While this part of the act was never strictly enforced (Mitchell & Mitchell, 1985:19), it still provided an opportunity for blackmail, increased surveillance, and initiated governance/regulation by suggestion. The power to compel parents to enrol their children in special classes was made more immediate via its transference to lower-level, departmental bureaucrats through the Education Amendment Act 1932/33. All previous Education Acts, their amendments and provisions were consolidated in the Education Act 1964.
In 1922, 'efficient and sufficient' education was made available through the correspondence school to children who, by reason of 'remoteness or handicap', could not attend standard or special educational facilities; day schools for cerebral palsied children were opened in Christchurch and Dunedin in 1949; in Wellington, Invercargill and Rotorua (in conjunction with the Cerebral Palsy Unit at Rotorua's Queen Elizabeth Hospital) in 1951; and, in Auckland, in 1952. Teachers, speech therapists, physiotherapists and occupational therapists staffed these schools. In 1954, Saint Dominic's, a Roman Catholic school, opened in Feilding for deaf children, and in 1958 the state run Kelston School opened in Auckland for children living north of New Plymouth. Sumner continues to cater for deaf children living south of New Plymouth. Homai College, a residential school for blind children, was established in Manurewa in 1964 (Kerse, 1972:108-21; Parsons, 1972:96-107; Mitchell, 1987:26-38).

It was not until 1960 that the policy of segregation began to soften with a class for deaf children being organized in a regular primary school in Wellington. Eleven years later the first class for physically disabled children, within the confines of an ordinary primary school, opened in Mt Roskill. In 1977, a similar class was established for secondary students in Mt Roskill Grammar School. In both cases the anomalous bodied children were allowed to spend part of the day with normal children in regular classrooms (Mitchell & Mitchell, 1985:58,72). These moves can, however, be seen as double edged. On the one hand they represented an advance, insofar as they demystified the anomalous body by bringing it into closer proximity to normal bodied children. But, ipso facto, comparisons could be made, differences noted, made real. Similarly, barriers, only partially removed, become all the more impenetrable, exacerbating the pain of isolation. Moreover, teams of 'special educators' continue to administer the anomalous body within normal confines. This partial removal of barriers and professional regulation was/is repeated again in the accommodation provided for the anomalous body outside the medical institutions.

Caring compounds?
In nineteenth century New Zealand families generally did not have the resources necessary for caring for their members who were severely physically disabled. The first home for these incurables was founded at Jerusalem on the upper Whanganui River in 1886 by Mother Aubert and her Daughters of Our Lady of Compassion. In 1899, they moved their Home of Compassion to Wellington, a more accessible location where need was greater. Here, they cared for people with a variety of physical and mental anomalies including cerebral palsy, spina bifida with hydrocephaly, scoliosis, paralysis, degenerative neuromuscular conditions.
A former resident (1953-60) related good fortune in admission to the Home of Compassion. Notwithstanding the fear experienced when first confronted by people with severe cerebral palsy or hydrocephaly, and the stigma of receiving charity ("we were called the "poor unfortunates"”), the option was either being dumped in an old people’s home, or to be sent to Kimberley Psychopaedic Hospital in Levin. Many people with severe physical disability ended up in Kimberley, an institution for children with intellectual disability and/or behavioural problems.

In 1957, the state accepted responsibility for the direct care of physically disabled people with the opening of the Pukeora Home for the Disabled. Formally a tuberculosis sanatorium, the Pukeora Home was quite isolated from the local community, and, being under the control of the Waipawa Hospital Board, it was run more like a hospital than a residential home for adolescents and younger adults. Former residents paint a grim picture of the strict enforcement of rules banning alcohol from the premises, any romantic or sexual relationships between residents, and any fraternization between staff and residents. Even as late as the 1970s, residents had little input into the running of Pukeora. Today, Pukeora Home specializes in the care of people who have sustained head injuries.

In the 1970s and 1980s new initiatives, more in keeping with changing ideology and the new ethos of deinstitutionalization, were tried. Private trusts worked to raise funds and build homes within community based settings where physically disabled people could live as independently as possible with help, if and when needed, available on site. Each resident had a private, self-contained unit in which to live as solitarily or communally as desired. The Laura Fergusson Trust established six such homes around New Zealand in the 1970s, and the Ryder-Cheshire Foundation two in the 1980s. While the aim of establishing these homes in the community was to facilitate integration, these aims have remained largely unfulfilled. Instead, they have become enclaves from which physically anomalous people might venture out, but which members of normal society seldom venture in. In short they remain largely places of segregation within the mainstream.
SUMMARY AND CONCLUSIONS

In an interview with Martin (1988), Michel Foucault noted the reaction his history of psychiatry had provoked from the psychiatric profession. He asked, rhetorically, how to differentiate a real science from a pseudoscience, and answered, 'a real science recognizes and accepts its own history without feeling attacked' (Martin, 1988:12). The particular reading of the services provided for the anomalous body in New Zealand that has been presented may well provoke such a response. Notwithstanding, the net effect of the provisions was to create segregated spaces for the containment of anomalous bodies; spaces in which non-anomalous, professional bodies preyed upon the anomalous body, measuring, extracting knowledge, assembling dossiers, refining technique, modifying behaviours, building careers and fields of study, producing docile, productive bodies. While ostensibly humanitarian in intent, it can be argued that these institutional arrangements had initially more to do with removing anomalous bodies from the mainstream for monitoring and checking their procreation than with medical care, education, or accommodation, and that these services remained contaminated by their origins.

This is not to argue for any conspiracy-type theory, but to note the recurrent patterns of segregation and control of the physically anomalous body in Aotearoa/New Zealand. Patterns of segregation, now justified by the specialized knowledges made possible by, and produced within, those segregated spaces; patterns of segregation that, when coupled with the policies of genetic counselling, the routine ultra-sound screening of pregnant women to detect foetal abnormalities, amniocentesis for women 'at risk' of carrying a baby with Down's syndrome, and subsequent counselling to abort if anomaly is detected, still reek of social Darwinism and the eugenic ideal; an ideal that has become an integral part of our social stock of knowledge, an ideal deeply embedded in the collective New Zealand psyche. Thanks for this is largely due to Truby King and the work of the Plunket Society which transported his ideology as material practice and technique into most New Zealand homes.

King's genius was his ability to translate eugenic principles into accessible language and concepts and then to package them as mothercraft, which, in turn, produced the iconic Truby King baby, the corporeal encapsulation of physical health and moral fitness. In this climate,

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29 Madness and Civilization (1961) in which he documented the fact that modern psychiatry and the mental institution had their origins in the empty lazar houses that were dotted throughout fifteenth century Europe.
there must have been something profoundly unsettling about the birth of a baby with congenital abnormality. One can imagine that such a baby/object would have been perceived as being in defiance of all that is right and proper, of transgressing all standards of decency, as morally subversive. The creation of segregated space was a practical solution to the problem of protecting society while at the same time providing care for the anomaly. People severely physically disabled later in life, through accident or illness, might not initially present the same ontological affront, but the attitudes and treatment they receive has been largely shaped by that directed at congenital anomalies/disability.

Of course, parents do not explicitly teach their children that physical disability is morally bad or is something to be avoided at all costs, but implicitly, by the stress on health and corporeal integrity, by the gaps, the things left unsaid, the silences, the embarrassments, the confusion of feelings evoked by the physically disabled body - pity and fear, compassion and revulsion. Attitudes and reactions which are bulwarked by today's incarnation of the Truby King baby: the body beautiful (see Chapter II), an icon to which homage is paid in the media and on the screen, a corporeality which attracts success, an icon which totally devalues the physically anomalous/disabled body. Drawing upon this social stock of knowledge, one can only see and create physical disability as an entirely negative state of being. Hence, in late capitalist society, where judgements of character and worth are increasingly being made on the basis of outer appearances, there is very little to recommend physical disability; it is the antithesis of corporeal legitimacy and, as such, marked out and excluded from the mainstream in a variety of ways.

Implications for the traumatic paraplegic
Against the background sketched in the preceding Chapters, and probably possessing only a hazy, cultural knowledge about physical disability, people have accidents and get paralysed, become an anomalous body, physically disabled, a paraplegic body. It is in the wider social environment that the paralysed body becomes a paraplegic body-subject. Burkitt (1991), offers a useful starting point with his comments on the process whereby all bodies become subjects:

... the basis of human difference and individual identity is to be found within society, in the social relations that exist between individuals. It is only in relations to others and the material world in which we live, that humans come to realize their separateness from all that surrounds them. Furthermore, it is only in realizing this separateness in relation to the others and the objects in our world, that we see ourselves mirrored in the ways in which we affect them.
or in how they respond to our actions. Human individuals can only make themselves into a subject to the extent to which they have become an object ...to the extent they have realized their own existence through the effect their actions have had in the world around them, or by making them into a distinct entity in the eyes of others. (Burkitt, 1991:189)

As the nascent paraplegic wheels down the street the cultural meanings of the 'body beautiful', the 'freak' and the 'freakshow', 'the deserving' and 'the undeserving', the 'cripple' and the 'able-bodied', 'independence' and 'dependence', 'disability' and 'the disabled', become more sharply focused, specific, personal. Later, in the solitude of his/her own room and from the perspective of a body which is incontinent and no longer ambulant, the paraplegic is able to reflect on the implications of these meanings for her/him in terms of who and what s/he has/might become. In Part Two, experiential accounts of the paraplegic body, self, society, and the interrelationships between them are examined for the effects they have on the ways traumatic paraplegics (re)constitute themselves as subjects.
PART TWO

GIVING VOICE TO THE
EXPERIENCE OF PARAPLEGIA
INTRODUCTION

I have decided to open Part Two with an account of my reactions to the people and subject material involved in this study. I do this primarily to locate myself in the study. I am a paraplegic and I cannot, nor would I want to, separate myself entirely from the content of the study. Indeed, it was as a possessor of 'insider' knowledge that many sources of rich personal information were made available to me. A secondary consideration is that my reflections might act as a bridge between the rather impersonal and somewhat removed accounts of Part One and the immediacy of the often deeply personal accounts of Part Two.

A personal note: data collection, the writing up process, and self
From the outset, this thesis was as much a journey inwards as one outwards. After some twenty years of living paraplegia it provided an opportunity to compare my experiences, my paraplegia, my self with other paraplegics, their experiences, their journeys as paraplegics. However, I was not really prepared for my reactions to the accounts I heard, especially when I was staying overnight in a motel room, far from home, alone with my thoughts and reflections. Nevertheless, these reactions were later to became valuable sources of data and insight in themselves. Notwithstanding, I was particularly pleased when my wife was able to accompany me on these trips.

With nine of the fifty interviewees having been paralysed for two or less years, nine up to five years, and a further fifteen less than ten years, some of the accounts were pretty raw. As these paraplegics spoke the reality and limitations of my paraplegia hit home. I tried to recapture the experiences of walking on the beach or through the bush, riding my motorcycle, the luxurious feelings of mud between my toes or the pleasures of sex with skin sensation.

I was appalled by the accounts of root pain and remember feeling wonderfully blessed that I could feel nothing below my break while simultaneously realizing that paraplegia was a lot more than my experience; I heard the pain of the men who questioned their masculinity because of their lost sexual and reproductive capabilities. I empathized with the women who spoke of bladder incontinence and the pain, the humiliation, the desolation, the tedium of wet

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1 In this account I speak as an insider and use technical terms which all readers might not be familiar with. However, all terms are fully explained in the following chapter.
pants - this had practically been my daily experience for a decade before the uritip became available. I did not have to be reminded, but I was, of the time consuming ritual of effecting a bowel movement, of the contingency of any bowel management programme.

Shortly, after beginning to write the accounts of the effects of chronic urinary tract infection, I ceased hearing them and began to live them, to feel like death warmed up. I had finished a course of Augmentin the week before, and thinking I had finally beaten the infection - even though the signs were there that I had not - did not bother to renew it; the body had the last word. And when I began researching and writing about decubitus ulcers, I was transported back to the time when I looked with horror in the mirror at the previous week’s graze that had transmogrified into a rather large, pusy hole in my buttock.

This is not to say that paraplegics generally sit around all day thinking about the various ways in which paraplegia intrudes upon their being. That is, not until another para comes along and provides them with a framework in which they can systematically examine the effects paraplegia has had on their lives, the way they view the world and the way paraplegia and the world has shaped new perceptions of themselves, a new way of being, a new subjectivity.

As I have already indicated, it was in listening to other paras that my paraplegia became real to me; real in the sense that the limitations it imposed on me became objectified through their words, their experiences. Further, many had agreed to be interviewed because they were very interested in plying a para of some twenty years for information about the 'paraplegic' experience. As I answered their questions on the process whereby my paraplegia became the norm for me, the difficulties of that experience were re-lived and, again, my paraplegia became objectified - but this time through my own words.

This objectification, of consciously living paraplegia, revealed to me the extent to which my life had become organized around my paraplegia and how I just lived my paraplegia without thinking about it. This was a valuable insight and was true of most of the paras in the study. They, too, had incorporated their paraplegia so much into their being that it had become normal, inseparable from them, had made the abnormal normal.

I have already mentioned the methodological dilemma presented when paras would ask me about my experiences in relation to a specific question before answering it themselves. This dilemma occurred in the first interview. Mindful of the need to be the 'objective' social scientist and not to provide any information which might influence the answer in a particular
way, I asked if she would mind if I answered any questions at the end of the interview. I felt extremely uncomfortable and authoritarian doing this; it broke our bond as paraplegics, placing me in the elevated position of *knower* and she in the inferior position of being *known*. But the interests of 'science' prevailed. At the end of the interview it became clear to me how extremely artificial it had been to return to the points I had earlier refused to comment on.

Later, in reflecting upon the position I had taken in that interview, I decided that it had been quite alienating and that rather than facilitating an open, frank, discussion it had stood in the way; it had tainted the interview. It seemed ludicrous that I, a fellow paraplegic, should not share my experiences with the paras I was interviewing at the moment of question: I resolved to respond immediately in future interviews. This I did in the next interview. I was delighted when, in response to my answer, the para said: 'Really. Well, it didn't happen like that to me and I didn't feel like that,' or words to that effect. On other occasions the response could be: 'Yeah. The same went down for me but it didn't make me feel the same about myself as it did you.' Obviously, I was not influencing the direction of their answers. By responding immediately to their questions a mutual reciprocity was established, dialogue opened, and, with dialogue, the possibility of serendipity.

On other occasions (usually in response to more personal questions) research subjects would respond, 'Well, you know what it's like,' or 'you know what it feels like,' rather than answer the question directly. In the interests of science I should have said, 'I know what it's like for me, but I don't know what it's like for you,' but I never did. It seemed to me that, apart from the questionable ethics of pushing people into answering questions they did not want to, to pursue such a line was highly exploitative. Also, implicit in the 'you know what it's like' response, was the direction to listen to myself and to what other paras had to say on the subject.

At the end of each interview I asked for comments on the interview, its contents and process. Some respondents wrote comments on their surveys. Two response follow, the first at the conclusion of an interview and the second from a survey:

Well its made me think, you know (pause) made me think sorta, like (pause) I've never really had anything like this before so I've had my say. (m,15,10)

This questionnaire brought out the deeper and inner things that I thought about my *self* which I thank you for letting me know. (emphasis added, m,20,2.5)
Chapter V
THE PARAPLEGIC BODY

PARAPLEGIA: THE PHYSICAL EFFECTS AND MEDICAL COMPLICATIONS

The physical effects on body function and the medical complications that follow spinal cord injury (SCI) are described in a fairly clinical and technical sense. Paraplegia is defined as paralysis of the lower limbs and part or whole of the trunk resulting from damage to the spinal cord. Paralysis may be complete or incomplete depending upon the type of lesion to the spinal cord. A complete lesion produces a total loss of motor and sensory function below the level of injury, whereas, in an incomplete lesion, certain amounts of motor and sensory function remain intact below the level of injury. The loss of control of the autonomic nervous system means that the control of the bladder, bowel, and sexual function is also lost. A brief review of the physical effects and medical complications of paraplegia follows.

Motor impairment

Different degrees of impairment result depending upon where and to what extent the spinal cord is injured. Generally the higher the break, the greater the neurological impairment. Figure 1.0, showing the vertebral column and the nerve supply to the body, indicates the functional consequences of lesions at various levels to the spinal cord. Quadriplegia (also called tetraplegia) results from lesions in the cervical (neck) region and involves varying degrees of paralysis to the four limbs. Paraplegia, that is paralysis in the lower extremities, is the outcome of injury at the thoracic, lumber, and sacral levels.

People with injuries between T1 and T6 have full use of their upper extremities and their hands. Since the spinal nerves between T1 and T6 control the chest muscles, people with injuries at T6 have better breathing ability. This loss of control over the abdominal muscles does, however, affect balance and trunk stability. This is not a problem for people with injury at the T12 level who have good abdominal control and excellent balance while sitting. While injuries to the thoracic and lumbar regions necessitate the use of a wheelchair for locomotion, they do not impede independence in all other activities of daily living. People with injuries at the L4 level and below may be able to walk with the use of leg braces and crutches or a cane (Trieschmann, 1988:13-15).
Sensory impairment

The ability to feel the sensations of touch, temperature, pain, and position is lost below the level of the lesion. This has important implications for the daily functioning and health of the organism as the body may sustain injury without the person being aware. S/he must constantly check temperatures to avoid burns or frostbite, monitor the body daily for cuts and scratches, and, above all else, avoid sustained pressure on bony parts of the body, especially the buttocks and sacral areas, heels, ankles, and hips. Creek et al. describe the health and medical implications of unrelieved pressure:
The worst and most striking complication of combined motor and sensory loss is the...pressure sore (or pressure area) and can occur sitting in a chair just as easily as sitting (or lying) in a bed. It results from ischaemia and involves tissues at all levels - skin, fat, muscle and bone. A pressure sore is due to the fact that the weight of the body exerts greater pressure on tissues underlying the bony points than the blood pressure can overcome. Tissues are rapidly rendered anoxic and destroyed, unless the blood flow is restored. If a sore involves only the skin, it is a matter of days or weeks before it heals. When the bone is involved, it may take months. Pressure sores are not sterile, they are septic and when organisms enter the blood stream septicaemia results. (Creek et al., 1987:8)

In the first instance a cure is effected by relieving pressure from the area of the decubitus ('decubitus ulcer' and 'pressure sore' will be used interchangeably henceforth). In the case of sores on the buttocks, sacral areas, and hips this will involve lying prone in bed for extended periods. In more severe cases involving an open wound or the bone surgical intervention is necessary.

**Bladder and bowel dysfunction**

The loss of voluntary control over the bladder and bowel is an immediate consequence of paraplegia. Initially urine is drained from the bladder via an indwelling catheter. Since indwelling catheters lead to infection, they are eventually removed and replaced with either a programme of intermittent catheterization or manual expression.  

Bladder management poses fewer problems for men than women. Men are able to use an external sheath/catheter which connects to a leg bag for urinary collection. No such external devices exist for women. Intermittent catheterization (insertion of a clean catheter through the urethra into the bladder to drain the urine) is also a less complicated procedure for men than women. Where there is chronic urine retention, damage is caused to the bladder musculature by overstretching, and back pressure changes are transmitted to the kidney leading to hydronephrosis. In these cases a sphincterotomy - an incision in the sphincter muscle between the bladder and urethra - is performed. This allows urine to flow freely from the bladder at all times. Because women are unable to wear an external sheath and leg bag sphincterotomies are restricted to male paraplegics (Creek et al., 1987; Trieschmann, 1988; Sullivan, 1990).

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1 This involves training the bladder to empty when tapped at regular intervals, usually four hourly. This is not always an entirely reliable method; 'accidents' do happen necessitating a shower and change of clothes. Cleanliness is also crucial in the prevention of pressure sores.
The maintenance of a healthy urinary system is of prime importance to paraplegic health. Paraplegics are prone to urinary tract infections (UTIs) because the bladder is seldom emptied completely, and the retained urine stagnates and forms the perfect medium for the growth of bugs. This tendency can be counteracted by the consumption of large quantities of fluids to flush out the bladder. An indwelling catheter increases the probability of bladder infections, and the loss of calcium from bones increases the chance of kidney and bladder stones (Creek et al., 1987; Trieschmann, 1988; Sullivan, 1990).

Since the bowel, like the bladder, is also paralysed, the paraplegic has to be taught to evacuate him/herself using various stimuli such as the fingers and/or suppositories. This has to be done every one, two, or three days in the morning or evenings. Once established this routine must be adhered to in order to avoid any embarrassing accidents.

**Sexual function**

Sexual function varies with sex, level of lesion, and completeness of break. For the female paraplegic, impairment of motor function does not prevent participation in sexual intercourse from a purely technical point of view. Restricted movement coupled with the loss of sensation may, however, alter the degree of physical pleasure experienced. Fertility is unimpaired and menstrual periods tend to resume within several months of injury; the probability of women with incomplete lesions experiencing the entire range of sexual pleasures increases. (Trieschmann, 1988:17).

SCI has a number of significant effects on male sexuality. For the sake of clarity and precision the work of Roberta Trieschmann, who has researched and written extensively in this area, is reproduced:

Nondisabled men experience erections on a psychogenic basis, that is, in response to sexual stimulus. In complete spinal injuries, erections do not occur in response to psychogenic stimulus. If they occur, it is by spinal reflex and, therefore, not on a voluntary basis and not emotionally related to a sexual situation. Men with complete spinal injuries in the cervical and thoracic areas usually experience reflexogenic erections ... in the lumber and sacral areas are not able to ... even on a reflex basis.... Fertility is usually impaired ... ejaculations may not occur [or] ... the semen may be ejected into the bladder .... (Trieschmann, 1988:17-18)

While many paraplegic men may experience difficulties in obtaining or maintaining an erection this does not preclude them from sexual activity. It does, however, have implications for their sense of 'manliness' and worth as a sexual partner. As with SCI women, the loss
of sensation greatly reduces the experience of physical pleasure usually associated with sexual intercourse.

Potential complications of SCI
A number of other factors should be considered when describing the corporeal sequelae of paraplegia. Pain, muscle spasm, and temperature regulation may have significant impact on the person’s daily activities, self-perception, meaning attached to paraplegia, and subjectivity.

Pain
There are potentially a number of sources of pain associated with paraplegia:

1. pain at the site of injury during the acute phase of rehabilitation. This usually abates over time;
2. damage to the lumber region requires the insertion of Harrington rods around the vertebrae as a means of support. These are frequently a source of pain or discomfort;
3. Paresthesias, the burning or tingling sensations along the nerve roots, may also be a source of pain (commonly known as root pain);
4. Hypesthesias or heightened sensitivity over certain areas of the body may or may not be a source of pain; it can double as a source of erotic stimulation during sexual encounters (ibid.:18).

Given that anaesthesia exists below the level of the break, that pain is consequently difficult to measure accurately in physiological terms, and that the incidence of pain must rely on verbal reports, many professional believe that pain is inconsistent with complete SCI and that it exists more in the mind of the paraplegic than in his or her body.

Muscle Spasm
After several weeks or months, SCI in the thoracic region may produce muscular activity of a reflexive, non-voluntary nature. The spasm can take a number of forms including: the thighs jerking spasmodically and violently upward without warning, the entire leg shaking rapidly causing the feet to tap frenetically on the foot plate of the chair, the extensor muscles contracting causing the legs to stiffen and extend directly out in front, contractions that tighten and lock the legs into place making them difficult to move when dressing or transferring from wheelchair to bed, car etc. The abdominal muscles are also subject to spasm which causes the entire trunk to go into rigor or throws the body violently forward; these spasms can be extremely painful. Similarly, the muscles in the back also spasm and contract throwing the whole trunk backwards.
Spasm can vary in intensity from being unnoticeable to being frequent and violent. Slight spasm can be beneficial in the terms of maintaining body tone, while violent spasm might require surgical or pharmaceutical intervention to allow the person to perform activities of daily living without the constant interference of spasm.

**Temperature Regulation**

For people with high thoracic (T4 -T6) injury body temperature is greatly influenced by external temperature. This results from a lack of vasoconstriction to conserve heat in cold climates, and an inability to perspire to vaporize heat in warm climates. Excessive sweating above the level of the lesion may be occasionally experienced by these people.

From the above it is evident that paraplegia should not be regarded solely as the loss of the normal function of motor power, the loss of sensation, and the loss of bladder and bowel control: the body is more than just the sum of its parts. The paralysed areas may develop complications such as root pain, pressure sores, or spasms and these intrude upon the person's consciousness and well-being and, thus, impair the function of the whole body. Since the body is the means of perceiving and living in the world, of organizing and co-ordinating sense data so that the world is made sensible and accessible to the conscious (Merleau-Ponty, 1962), specialized rehabilitation programmes aimed at the survival and the restoration of productivity to the radically transformed, paraplegic body are required. For the people in this study, this process began in Auckland at the Otara Spinal Unit.

In the remainder of this chapter paraplegics give voice to their experiences in the Spinal Unit. In many of these accounts there is a tension between the critique of the regimes of surveillance, discipline, and normalization that their bodies were subjected to in the Spinal Unit and how they themselves were experiencing their bodies as subjects. While these critiques might well have policy implications for the Spinal Unit, they are not presented here for that purpose. My focus remains on the phenomenology of the paraplegic body. Thus, in the context of this chapter, a phenomenological analysis of the paraplegic body, the criticisms should be read as a part of the larger resistance to paraplegia and being paraplegic. In this sense, the Spinal Unit presents itself as an institution which can be changed as opposed to the immutability of paraplegia. The actual techniques of body maintenance, which the Spinal Unit imparts, are never so much in question as is the way in which they are imparted. At the most obvious level, what appears to be at stake is the institutional understanding of paraplegia as opposed to the personal, phenomenological experience of paraplegia. At a deeper level, the tension resides between the way the former
shapes the latter: of remaining an individual subject as opposed to becoming an undifferentiated, paraplegic body-subject².

LEARNING TO LIVE A PARAPLEGIC BODY: THE OTARA SPINAL UNIT

The Otara Spinal Unit is situated in South Auckland in a mixed light industrial and residential area. It is flanked on one side by an area of bushy wasteland and on the other by a brewery. In one direction, a liquor wholesaler, a warehouse for a large supermarket chain, and a number of used car lots gradually give way to older, untidy housing. In the other direction, state housing stretches for miles. It is a generally depressed, low socio-economic area with high rates of unemployment and poverty. The Otara Spinal Unit is linked to Middlemore, an orthopaedic hospital some five or so kilometres away. Middlemore supplies a variety of ancillary services to the Spinal Unit.

Admission: subjugation to medical power

Admission to the Otara Spinal Unit marks the institutional phase of a person's rehabilitation. A number of patients are admitted with some knowledge of paraplegia, having received acute care at a hospital elsewhere. The majority are admitted directly, in a dependent, bewildered, and frightened state of mind knowing only that they can not feel or move their legs. The body is out of control: even more mysterious, what does this mean? how am I going to survive? The purpose of the Otara Spinal Unit is to provide answers to these questions, to train these people in techniques that will enable them to live their paralysed bodies in a productive way, to rehabilitate their bodies, to prepare the embodied self for a way of life that was inconceivable a day or two ago. Rehabilitation, however, is a concept which promises more to nascent paraplegics than it can hope to deliver within an institutional setting.

Medical power is quickly asserted over the new admissions, particularly those still in the acute phase. These patients³ quickly learn that not only have they lost the power to move

² Mutatis mutandis, the same applies to reading the accounts in Chapter VIII, especially those in the sections on the Accident Compensation Commission, the welfare bureaucracy, and income support, which contain critiques which have implications for policy.

³ The term 'patient/s' is used throughout this section in spite of the current fad to dress the term up as 'clients'. People in the Otara Spinal Unit/hospitals remain 'patients', the power relationship between the providers and receivers of public health services remains essentially the same as it always has been. To use 'client' when we mean 'patient' is highly ideological.
and feel their bodies but that they have lost possession of it in terms of knowledge and control. Medical professionals know how the patient should feel (they have read the right textbooks) what the patient needs, and, moreover, are in a position to enforce their diagnoses. The paraplegic quickly finds that s/he is now in a space where medical knowledge and medical power prevails. For example, take this woman's introduction to the Spinal Unit:

... the first day that I got moved to the Spinal Unit they were used to having these sort of 6 foot 2 rugby players so they laid me on pillows and there was pillow to spare as I'm that much shorter than most of the people that have been in there. So they said, "we must have laid her wrong." So they lifted me up and laid me again. And it ended up so they had a bit of me on each of the pillows but it meant that I didn't have a pillow under my fracture side. So it was really, really painful. And the way you get to go to the spinal unit is that if you actually get off morphine because they won't take you if you are on too heavy pain killers. So I knew that they didn't give me pain killers so I said, "I don't think you've laid me right" And they said, "well how would you know? You've just arrived here." And I said, "well I can see by the diagram that you're working from that I'm not in the right position", and they said, "well that's it. We've moved the team now and we have to do a full team lift, so you're stuck like that". And it was really, really painful so I said, "Oh well, what's your position on pain relief here?" And she said, "are you in pain?" and I said "yes" and she said, "that's good because it means you've got feeling doesn't it?" and walked off. And I just had to lie there in agony until the afternoon shift came on.... I arrived there about ten o'clock and the afternoon shift comes on at three ... and it was painful and I was crying with pain. And the afternoon shift came on and the first thing the nurse said [was] "Oh, you haven't been laid right. We're going to have to organize a full team lift to get you laid right". So that was my introduction and I just thought, so thats it! (f,22,1.5)

Another person experienced similar treatment on admission. This person had sustained the injury a fortnight previously in another city. Numerous X-rays had detected nothing despite the continuing pain. Given that someone else was killed in the accident and that criminal charges were pending, the pain was attributed to imagination; an obvious grab for mitigating sympathy. This person's story had preceded him/her to the spinal unit: 'The day I arrived there I had a neck roll in - I had a sore neck - and they just whipped that out: "No, you shouldn't have that. There's no need for that."' The rough justice continued:

... when I sat up I couldn't even hold my head up properly. And when they were doing full turn lifts I used to plead with them to hold my head for me and they said, "No. You should be able to hold it for yourself." But I could never do any of that ... they didn't even want to admit that there was any injury there.... numerous times [I complained]. They said, "Oh, you've been through a lot"... (f,21,1.5)
Ten weeks after the injury, evidence of damage to the cervical area at C3 was finally obtained and appropriate treatment followed. However, in spite of the decreased sensation and strength in the right arm, this patient's account of his/her body was ignored by the professionals. Moral judgements seem to have precluded immediate and objective medical exploration of the symptoms.

Two further instances of the deployment of medical power illustrate its subjugating and alienating effect. In the first episode, a woman is denied dialogue on her diagnosis, treatment, and rehabilitation programme:

... I queried an orthopaedic surgeon and he went right off his face, ... and all I was doing was asking a question and he said, "don't you give in and how dare you judge or criticize my judgement or query my judgement." And I thought who do you think you are, God or something? And yet if you asked about what was happening with you or something [it was] like ... a guy there who had heaps of trouble with pain.... he just wanted to find out what they had found out, and it was like: "don't worry about it because we will fix it - it has got nothing to do with you" type of thing. (f,23,2)

As the above demonstrates, medical power and control was pervasive: patients had little, if any, meaningful input into their rehabilitation programme. They were inserted into pre-existing programmes, with little allowance being made for individual abilities and differences. Adding to the frustration of this 'doctor knows best' attitude, was the lack of in-depth information on the immediate and long term effects of paraplegia, the current treatment, and progress individuals were making. The general feeling was that the medical experts either did not know or, for some unfathomable reason, were withholding information about their paralysed bodies and their future lives. Information, when given, was often contradictory. In effect, patients were kept in a twilight world, where no clear answers to their questions were given:

I was kept in the dark too much. I wanted to know what the future really held in store. I feel the patients rights ... were crushed.... I resented most of the attitudes that were shown by the trained staff. It felt as though I was in a prison rather than being nursed back to health. (m,23,7)

In this environment, the paraplegic body became increasingly mysterious, and life and self evermore tenuous and contingent.
Another way in which medical power was deployed in an abusive and demeaning way is captured in the following account:

... some nurses can be real mean to people when they are first paralysed in here. Like they treat you like little kids. They make fun out of you sometimes ... they go overboard....They tip you out in the middle of the floor sort of thing, leave you there sort of thing, or crack jokes at you all the time. Just generally be mean. (m,18,14)

Such an obvious example of the abuse of power needs little explanation. While the throwing of paraplegics out of their chairs might serve as a rite of passage (see below p.163), it is primarily about establishing hierarchies of authority over individual bodies, breaking resistance, pushing boundaries, the professional control of a population within a defined space. However, my informant offered another interpretation:

... It certainly works on some people .... make[s] them get angry and either pull their finger out and get the hell out of here which it's designed to do....

But the unanswered question is: what does this abuse of power do to those it does not work on? The message is probably clear to such people: you are now worthless, powerless, vulnerable. For the sake of these people such behaviour should be abandoned because:

... the patient who comes in here has just had the most dramatic thing happen to him in his life. His whole lifestyle is completely changed just like that. And they should be given a bit more respect and a bit more help. (m,18,14)

Not all the people I spoke to had such a negative memories of the spinal unit. A sizable minority, forty-one percent, enthused about the programmes of physical rehabilitation, attitudes and the behaviour of the staff. Comments such as: '... an excellent place for rehabilitation and motivation'; '...Spinal Unit was the highlight of my hospitalization'; '...brilliant staff', were, however, most likely to come from males and people who were older at the time of accident. This might be explained by the fact that males generally had an easier lot in establishing regimes of bladder management (see below), were generally stronger and more inclined to the physical, and were not burdened with the double disadvantage of being disabled and female in a disableist and sexist society. Older people, who had lived most of their lives, had raised families, had established careers and friendships, and, thus, had a wider support network, tended to adopt a more pragmatic approach to their paraplegia and the rehabilitation programme:
... Providing you did what you were told - they said it for a reason - and you don't answer them back, then they treated you right. (m,44,6)

This implies an acceptance of medical power and the discipline it imposes upon the paraplegic body, an acceptance that medical power is productive. The accommodation of paraplegia, the restoration of productivity to the paraplegic body, is very much dependent upon the imposition of routine and regularity on the excretion of bodily waste. Curiously, the paraplegic's overriding concern with this facet of bodily function harks back to Truby King and his obsession with the need to stamp discipline and regularity of movement in baby's bowel. The frustration those mothers must have felt as they 'held baby out' after the ten a.m. feed and waited for its bowels to move, is, perhaps, equalled by the newly paralysed person as s/he establishes a regime of bowel management.

**Regime of the bowel**

Many of the paraplegics I spoke to did not go into any great detail about the hassles associated with bowel control. They tended to brush over it in a slightly embarrassed way indicating that I, as a fellow paraplegic, knew all about the tensions associated with living this reality. This surprised me, given that whenever I had been with other paras it was only a matter of time before someone raised the issue of bladder and bowels, thus beginning a round of stories and experiences - usually told in pretty graphic detail. The stories were always tinged with hurt and humour: at a distance these socially devastating and painfully embarrassing 'accidents' could be laughed at, communally shared, deconstructed by the 'wise'.

One of the first things the nascent paraplegic is taught is that conscious responsibility must be taken for emptying the bowel. Usually it is sufficient to do this every second or third morning using suppositories or by stimulating the sphincter muscle around the anus with a finger. A 'successful' bowel motion may involve the insertion of a gloved finger into the rectum and manually removing the stool. It is advisable to do this anyway, just to make sure. A programme of bowel management begins while the person is still in bed during the acute recovery stage. All of the above is generally done to the paralysed body by a nurse or nurse aide. The patient is then left in bed to defecate onto an incontinent sheet. The nurse may have to return to perform a 'manual'. When finished the patient is 'cleaned-up' by the nurse.

This is an incredibly hard lesson to learn, it drives home the reality that self no longer controls fundamental bodily processes, that, albeit temporarily, others are doing things to the (my) body which are humiliating, dehumanizing. The only way to handle this is to distance
self from body by objectifying it as a removed, unfeeling, body which does not represent self. The Cartesian dualism prevails with the subject being locked in a fleshy prison from which s/he cannot escape. The bowel and its contents is one dimension of that prison. A man, who had only been paralysed for ten months, explains what living in that dimension is like:

... I've found it frightening to go out.... X asked me out the other week. I got up in the morning and bowel care - one of the biggest worries at the moment. I go on the toilet in the morning and then an hour later I feel as if I need to go again. If I'm going out that day I go back and check again. And I just worry about it all the time I'm out. I worry that I'm going to be dirty. And smelly. I worry about that.... When I went to hospital they took me in an ambulance ... and this old chap got in ... and he stunk. And I thought God, am I going to get like that? Things like that, they worry me. (m,20,10 months)

Other paras told similar stories; of the fundamental fear of 'shitting' themselves in public, of the absolute necessity of getting a good bowel management routine going. While that necessity was recognized, the process of inculcation was resented:

They've got a bad problem there. You get up at this time on this day to do your bowel motions ... [imposing] a kind of military routine. Up at six, toilet, out of the toilet by half past seven, shower then down to breakfast by eight.... I do bowel motions either at night or the morning. With them you had to do it in the morning. (m,20,2)

This is just one example of the views expressed by most paraplegics when speaking about their bladder and bowel training. The aim of the exercise was never disputed, just the means. What was resented, and resisted, was the authoritarian approach, the complete lack of flexibility, the regularizing, the totalizing effects of being normalized as paraplegic which denied them any sense of ownership and control over their bodies and their situation.

From the outside one may observe that this is precisely the Spinal Unit's job; to provide the framework within which the newly paralysed person is taught to manage fundamental bodily processes, to restore productivity to the body; to become a paraplegic. Once established, however, the routine of bowel management tends to dominate and life loses much of its flexibility and spontaneity.

I think that the significance of the loss of bowel function for paras is nicely summed up in a conversation which ensued between two young male paras when I was in hospital. They were debating the first thing each would do if miraculously cured. ‘I'd probably masturbate'
said one. 'Nah. I'd go and have a good shit,' said the other. 'Oh yeah,' rejoined the first para, 'that's what I'd do too.'

**Bladder Training: power, control, and insensitivity**

As with the bowel, the bladder is also paralysed and the paraplegic usually has no control whatsoever over its operation. It is crucial, therefore, to institute a system of bladder management as quickly as possible. Apart from the psychological aspects there are a number of health issues involved. In the interest of maintaining a healthy urinary system, the paraplegic must drink plenty to flush the bladder continually. Urine sodden pants do not do much for personal hygiene or sense of well-being. More importantly, urine is quite corrosive and the skin quickly breaks down into ulcers if continually wet.

Males present fewer problems than females in bladder management. In the first instance, they are able to wear an external catheter. The Urisheath or uritip, which resembles a condom with an outlet tube, is rolled onto the penis and, if not of the self-adhesive variety, attached by tape or surgical glue. The outlet tube connects to a leg-bag in which the urine collects. A tap allows the bag to be emptied. Overall, this is pretty reliable technology. When fitted anew each morning, the paraplegic male can look forward to a dry day with some confidence. But accidents do happen, and no male paraplegic can ever be one hundred percent sure of remaining dry throughout the day.

Prior to the arrival of this technology (early 1980s), men had to make do with a far less reliable system. The 'Davol' was a bulky, sheath-like arrangement that was held in place with a system of straps and belts. Because it was soaked overnight in disinfectant to kill any bugs, the Davol had a peculiar odour. These two features, its bulkiness and smell, made the wearer constantly aware of his incontinent status. This became depressingly obvious to most over the course of the day (and frequently during the night when a bottle was used). Given that the penis relied on friction to hold it in the Davol, and given the penis's tendency to shrink and retract as the bladder fills, inevitably the penis would shrink out of the sheath and wet pants would result. One older para spoke ruefully on the subject of 'flashbacks':

> You can be sitting there with wet pants and no-one will know eh? But you know. Boy, and if you've got a bit of an infection it stinks! (m,19,8)

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4 'Older' does not relate to age in years, but to length of time paralysed--at least six years. For example, a 'younger' para may be sixty years of age while an 'older' para might only be twenty-one.
Some males had experienced problems with urine retention and had had sphincterotomies when in the Unit. They were young at the time and now complain bitterly that they were not counselled as to the full implications of such an operation:

I've had one of those [sphincterotomy] 'cause I was told I needed one. I wasn't really told what was, what it would mean. The arrogance, doctors man. Arrogant bastards. (m,19,12)

One para, who was 15 years old at the time, complained:

I felt that I was a guinea pig for those to come ... that's what I felt cos, OK - did they give you a sphincterotomy?

No.
They gave me one. And they didn't have to.

They didn't even ask you?
Yeah they did. But I was so young, you know. They went to my parents and they just said "yes." It's for his good, you know. My parents didn't know what it was, you know? They should have come and fucking asked me and told me eh? ... They [doctors] just said you're going in for an operation. Here it is all signed sealed by your parents, eh? Not a lot of things were explained to me ... So I felt like a guinea pig. (m,15,10)

Besides dribbling all the time, love-making with a 'free-flowing' bladder is awkward, embarrassing, requires explanation, is generally off-putting, especially to any potential partner, whose attitude may be wrongly guessed.

The problems of male paras, however, pale into insignificance when placed alongside those experience by female paraplegics in relation to bladder management. Women cannot wear external sheaths and the use of indwelling catheters increases the risk of infection. Attempts are made to train the bladder to empty itself at regular intervals through intermittent catherization or manual expression of urine. Accidents do happen and the training period is generally a degrading and depressing time for female paras. These are adult women with adult sensibility, sensitivity, and pride who, like infants and young children, are in 'leaky' bodies over which they have little control. One woman explains what bladder incontinence means to her:

... people don't realize. They can't appreciate how it really can be. To me, its the worst thing. The most humiliating and worst thing of it, is that. I can live with not walking [but] ... if it wasn't for that then life in a wheelchair wouldn't be so bad. (f,23,2)
Later, this woman explained why bladder incontinence was/is the worst aspect of paraplegia for her:

... it certainly doesn't make you feel good about yourself.... it doesn't do much for your self-confidence.

One would expect a spinal unit to be a generally safe and supportive environment in which females could learn techniques of bladder management. Unfortunately this was not always so. A number of women told horror stories about the bladder training programmes inflicted upon them. The first woman believes her whole rehabilitation was held up by the inflexible approaches adopted:

To me its [bladder training] the most humiliating and worst thing ... I'm annoyed they let me put up with it for so long. Being wet all the time. It did nothing for my confidence. I kept saying, "Give me an indwelling [catheter]" and they wouldn't let me have it. I'd want to go out for the day and I'd ask for an indwelling and they'd say "no", so I didn't go.... that was the reason I was in there so long ... because I could never do any physio 'cos I'd go over there and I'd be wet....  (f,23,2)

Another woman spoke of the confused and confusing advice she was given, the depersonalized manner in which nurses delivered it, and the messages this mode of delivery imparted to her about her body:

... when I was doing bladder training there was no one nurse teaching you. I had about six different nurses with six different approaches and that's really hard. And something, especially like that its quite private. And you don't get privacy out there.... One nurse will come in and another will come in to talk to her. And you're thinking, "Shit ... its just another body." And because they're so used to it they expect you to be used to it too.  (f,21,1.5)

A more disturbing tale came from a rather forthright woman who was in her early twenties at the time:

... It's such a mickey mouse outfit. I was on intermittent catheters, so I started doing a catheter and someone came in and said "No! You should be doing this".... four people came in and told me to do something different ... I was adamant I had an indwelling catheter as ... I was flooding all the time. All I was doing was pissing myself, showering, changing. I had a really bad UTI and the way I feel that you get rid of a UTI is to push fluids and you can't push fluids if you're on intermittent catheters. So I said, "give me an indwelling catheter until I get rid of my UTI" and they said "no".... So anyway I just stole one and put it in and they got really upset and took it out in my sleep - which I was just SO upset about. So they thought that it was fine that I was spending my entire life pissing, showering, changing. And that's all I had time
for. I was absolutely suicidal, I was just so low ... I will not ever be subjected to that ... again. (f.22,1.5)

To cap it all off, bladder training exacts a far greater price from women, both psychologically and physically, than it does from men. As one women explained: 'I was doing it [intermittent catheterization] four hourly, twenty-four hours a day ... perpetual tiredness where you just don't cope with anything. But the thing I really objected to was when the urologist wouldn't listen to me when I said I'd rather be dead than live like this.... The way women get treated there.'

The above accounts capture the essence of the disempowering effects of incontinence. Many of the paras I spoke to (female and male) nominated incontinence as the worst aspect of paraplegia for them. Incontinence, coupled with a loss of skin sensation, clearly establishes the mind/body dualism in a way which is unfathomable to the uninitiated. It tears the soul from the body, showing the most excessive and unruly aspects of the body: one has to become mechanical, disembodied in a sense, to cope with the fleshiness of one's own body. The paralysed body-subject, already feeling pretty powerless, is made to feel even more so as a model of management is imposed upon the body, in a way which takes no account of the subject's personal needs or feelings. If more sensitivity had been shown by staff, in listening to what patients were saying, then much of the trauma mentioned could have been avoided. This seemingly callous approach by staff is a manifestation of the extreme prioritizing of the corporeal over the psychological at the Spinal Unit. The totalizing aspects of physical rehabilitation are discussed at length below.

While a reliable regime of bladder and bowel management is necessary for the survival of the paraplegic body-subject, it is not sufficient. The subject must take special care to keep the body alive.

MAINTAINING THE PARAPLEGIC BODY: HEALTH AND HEALTH CARE

Good health is the precondition for much of what we do. Our experience, the way we perceive ourselves, the satisfaction we derive from living, our career opportunities, social networks, and recreational activities are all ultimately determined by the state of one's health.

Most people, particularly younger people, are too busy leading their lives to stop and appreciate that without their good health, their lives might be entirely different. The annual
'flu' epidemic may cause some temporary inconvenience, but generally, bodily processes, functionality, and health are taken for granted and life goes on. Sickness is not part of their being. Nor should it be following paralysis. But avoiding sickness, managing the body so that fullness of health and lifestyle are achieved, is very much part of the paraplegic being.

Paraplegia is not an illness that can be cured. It is a chronic condition that can be managed. Thus, the serious medical complications associated with paraplegia, which were outlined above, can be avoided or minimized to some extent. The necessary body management skills are inculcated as part of the subject's rehabilitation programme at the spinal unit. Foremost amongst those techniques are those associated with maintaining the integrity of the skin.

Limiting life and self: pressure areas and pressure sores

In the armed forces sunburn is treated as a self-inflicted wound, an offence subject to court martial. Pressure areas are viewed in similar light by the director of the Spinal Unit, Dr O.R. Nicholson. For him, paraplegics should not get pressure areas. There is no excuse. Pressure areas are the result of self-neglect, they are self-inflicted wounds and the paraplegic with a pressure sore elicits no sympathy from Dr Nicholson.

Education about pressure areas begins early in the rehabilitation process. Patients are instructed in what they are, their cause, how to avoid them, how to detect them in the early stages of development (check your buttocks, hips and heels every night; rub any red areas with Vitamin A ointment to restore circulation and nourish the skin; if an area has darkened past the red stage to black, breakdown is imminent - get off your backside immediately and stay on bed rest until normal colour returns). Graphic colour photographs of fully blown pressure sores are then produced: angry, gaping holes with pusy, rotting flesh, devouring as much as a whole buttock, sometimes both buttocks and the sacral area (Figure 2.0). Imagine the photo below in colour and feel the fear. This is living death, shock tactics designed to show the contingency of the paraplegic body.

The horror of pressure areas is something the paraplegic body-subject is never allowed to forget while in the spinal unit: continual reminders to check, to shift body-weight to relieve

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4 As a former patient of Dr Nicholson I know this from personal experience. A year after I was discharged from hospital I reported to him as an out-patient with a pressure area. He literally turned purple and dismissed me telling me that I had no right to turn up to see him in this state, that he was not going to admit me for further care but to come back the following week. I returned the following week to find that he had gone on holiday, but his offsider, a plastic surgeon, admitted me for surgery. While I suspect this was prearranged, there was no mistaking Dr Nicholson's message.
pressure, to take care while transferring from chair to shower, toilet, floor for physio, and so on. Watching over, monitoring the body, fearing tissue breakdown, are survival techniques inscribed on the paraplegic body as it is known within the medical discourse and as it becomes known to the paraplegic body-subject.

Figure 2.0
Large sacral pressure sore and small, but fully developed trochanteric pressure sore measuring 3.5 cm in diameter. (Source: Hardy and Elson, 1976: 70, 98)

In some cases the programming is too successful. As in the case of a para (m,20,10mths) recently discharged from the Unit: ‘your skin care and checking for sores and all this tends to worry you....You have to worry about everything.’ Another, (f,36,2.5) spoke of her fear of getting one of those ‘dreaded pressure points’ and her hope of never getting one. Another (m,27,7), ‘I’m paranoid about getting a pressure area....Once I rubbed a bit of skin off my
bum...and was confined to bed for about two weeks.' In some extreme cases, the body does not forget the dreadful experience of a pressure area. Take Jack (m,18,14), for example. His health has been 'excellent' apart from pressure areas:

Have your attitudes and approaches to health care changed at all since your accident?
No....only I guess if you call health not having pressure areas. That's changed because I make sure I get off my butt so I don't have pressure areas...

Changed [life] dramatically...like I won't - if I know some function is coming up and I know I'm going to be up all day - I'll most probably stay in bed as long as I can before I get up to go or...I must make sure that I have a lie down somewhere to get off my butt and give myself some rest.

Do you think you're a bit paranoid about pressure areas?
Yes. I definitely am because I know if I get another one I'll just go down so fast mentally. I just do not want to spend more time in bed.

How does all this...affect the way you see yourself?
I think it's affected it badly because, you know it's affected relationships. They'll say, "you're always having a bloody lie down. You never want to go here, there or anywhere because you don't want to spend too much time on your butt." So yeah, it has affected it a great deal.

Has this tended to isolate you?
I would say yes because like ...maybe I don't want to make a commitment because of the problems that I have.

Like with a woman?
Yeah.

But you've been on and off with this girl for eight years now. Have you ever discussed this aspect with her?
Oh yes, heaps.

And what is her reaction?
It comes and goes. I think she's sort of adapted slightly to it and then something will come up where she wants to go out and she'll get all pissed off because of my attitude towards pressure areas and all that sort of thing.

....she gets pissed off. Does this affect how you feel about yourself?
Yes. Certainly. I would say yes. Sometimes I say "right we'll do it" sort of thing and I'll take the risk and sometimes I'll say "oh stuff you" and bugger off sort of thing.

Do you think that maybe you are over-reacting to the pressure areas and would you like to feel free of this over-reaction?
Yes. I think about that quite often. That maybe I am making sure that I'll lie down for too long during the day and may be I should take more risks and stay up longer. Yeah, I would think about that quite often.
Do you feel that if you did take that risk and got a pressure area [that] it would be disastrous for you?
Absolutely, yes.

In what way?
Mentally. If I got another area and I had to spend a week even, or a month in bed I’d be so pissed off with myself; I’d just go whoosh [makes exaggerated, downward gesture with hand].

How long since you had a PA [pressure area]?
I haven’t had a major one since I had my operation in 1980. I’ve had a couple of minor ones where I’ve spent maybe three days in bed and that was enough.

So eight years without PA is a pretty good track record?
And I want to keep it!

Even if it means you are paying for it in terms of your relationship?
Yes. It certainly is. Because, if I have pressure areas for more than a week I’d go downhill fast, mentally.

In this case it is evident that Jack’s body, life, and being are dominated by the memory and fear of pressure areas. Identity, self-perception, now turns around not having a pressure area and the fear of getting one so much so that he is willing to forego normal social intercourse, to sacrifice an intimate personal relationship to avoid getting another pressure sore. Even after an eight year absence of any major skin problems, he is still haunted by the memory of that first pressure area which required hospitalization and surgery. The memory of the body, unmoving, unfeeling, breaking down, ulcerating, rot setting in, of being invaded by some alien and pernicious force, of not being sick, but of definitely not being well: of the body, my body!, being passed into the care and control of medical professions; the surgery, the boredom of the weeks or months of bed rest; the waste of time; the infantilization associated with having to defecate, wash/get washed in bed; the memory of being stripped of privacy; of having the most intimate of things done to your body in public, of being processed, and all the time feeling, or being made to feel, guilty, responsible. Such memories suffuse the body and being of Jack with his sense of self and subjectivity resting overwhelmingly upon the integrity of his body. Indeed, so indelible, so deeply etched are those memories, that one could argue that Jack, this paraplegic body-subject, has not been without a pressure area in the intervening eight years and that he is never likely to be without one. A clearer example of what Merleau-Ponty meant by the ‘body-subject’ would be difficult to find.

While over fifty percent (Table 2.0:288) of the total sample had experienced a pressure area at some stage since getting paralysed, only one other to whom I had spoke went to anywhere
near the same extremes as Jack. This person had yet to have a pressure area but lived in fear of getting one. Holding a managerial position, his career depended upon the maintenance of skin integrity, so every afternoon time was taken out so he could get off his 'butt'. No travel (business or recreation) was undertaken unless a bed with a particular type of mattress could be guaranteed. Similar precautions are mostly taken by those who have had a pressure sore, experienced the frustration of bed rest, daily dressings by visiting district nurses, the fear of the sore developing into a 'big-one', the time it takes to heal, the inconvenience, and so on. Once healed, the tedium of pressure sore care and the vulnerability of scar tissue, which so easily 'breaks down', are constant reminders to the paraplegic that s/he must monitor closely what is done with, how, and to the body. Paradoxically, the paraplegic body is now experienced more keenly, lived more fully as self, while simultaneously it is objectified as unfeeling flesh so that the body-subject might live.

It is useful at this point to contrast the (ongoing) pressure area experience of Jack with that of a male para of ten years, Warren. When I interviewed Warren he was in bed, on bed rest with his first pressure sore. When asked about his pressure area consciousness during the ten years leading up to this point, he replied:

I don't think about it ... I don't think about getting pressure sores, you know? That's why it surprised me. It really did, eh? (m,15,10)

This pressure sore had not caused him to reconstitute his sense of self in any way. Rather, it had caused him to refocus on the corporeality of his paraplegia and the restrictions it placed on his doing and being as his body broke down:

I don't think I'm a fucking useless paraplegic. I say "fucking pressure area," man! You know that's what I think. I think "fucking area" you know? And "fucking hygiene," man. I wish "Fuck. If it would just heal up and go away." Then I could just carry on and do what I want to do, eh? There's a lot of things I want to go out and do, ... and see - still. I just want this to clear up and get it out of the way.... (m,15,10)

While having a pressure sore might not have changed Warren's self-perception, it had certainly changed his attitude towards his body. He planned to be 'super careful', to get various aids to substitute, supplement, extend the body's health: 'I'm going to get me a Jay
Active cushion\(^5\)...I'm going to get me the works....' One could venture that Warren's planned prioritization of the body might, in the long run, change the way he constitutes self.

Some weeks after speaking with Warren, his pressure sores turned gangrenous and he was rushed to hospital where he nearly died. I visited a rather subdued Warren in hospital where we had a generalized discussion about his treatment and progress. After he was discharged we met up to do some roadwork (jogging for non-disabled). While we did not talk about the effects of his pressure sores and hospitalization on self-perception, I learned during the course of the evening that his budding relationship had subsequently foundered and that this was a major disappointment for him. I also noticed that he had lost some of his spark, his 'get up and go for it at any cost' attitude. All in all he seemed a lot more reflective, cautious, careful. Only time will tell if this was an immediate and temporary effect on self or if he was a changed subject. In any event, Warren's pressure sores and brush with death was a salutary lesson: the paraplegic body cannot be taken for granted, it demands a particular sense of self, it retains an acute memory of decubitus ulcers, underlining the fact that the paraplegic 'I' is ultimately a body-subject.

Pressure sores occupy a position all of their own in the overall health framework of the paraplegics I spoke to. When asked how their general health had been since their accidents, the following was a typical response of those who had had a pressure sore, 'Really good, you know like not bringing pressure sores and that into it.' This indicates that as time passes without any skin breakdown, pressure areas become a matter of the pre-conscious for most paraplegics and are bracketed out of the health arena. Sure, pressure areas/sores are imminent to the paraplegic body, but they are mostly experienced only once as a major event (that is enough) or periodically as minor grazes or scratches to the buttocks. In the latter case, the immediate removal of pressure is a crucial, preventative measure to stop the development of a major area. In either situation, pressure sores cannot be felt, but they can be seen; they generally do not make you sick but are potentially life-threatening; while one is not ill, one is certainly not well; elaborate rituals of cleansing and dressing the area must be followed daily. Given these characteristics, pressure sores do not easily fit conventional health frameworks. Consequently, one does not say 'I am sick' but 'I have a pressure area.'

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\(^5\) A lightweight moulded foam cushion with a heavier "Flolite Pad" of liquid silicon gel which is sat upon. The Flolite Pad acts as an extra layer of fat, absorbing and dissipating pressure making it possible for a para to sit for long periods without any ill effects. Such technologies raise a number of interesting questions about the boundaries of the paraplegic body, where it starts and when it ends, how and what actually constitutes it? These issues are addressed in the following chapter.
They are more a body-effect of paraplegia, a surface impression, a question of corporeal wellness or corporeal easiness, rather than one of health.

Pressure sores do, however, have a moral dimension so they do have implications for sense of self, a sense of how others perceive self and read one's character. As mentioned earlier, medical professionals couch pressure areas in terms of 'self-neglect' rather than 'body-neglect'. The possible implications being that this person just feels sorry for her/himself; that s/he is just plain lazy, incompetent, a no-hoper, wanting attention, can't hack it, is giving up. Similarly, one has doubts about self as one's standard of self-care is called into question by other paraplegics, who generally buy into the medical, 'self-neglect' scenario. That is, until they get a pressure area themselves:

I always thought that people who got pressure areas were, didn't look after themselves. And I got a pressure area and you know, [I used to] get up off my cushion and that religiously and then I got a pressure area...I used to bath twice a day and I thought, "Jesus, something's going wrong here."...it wasn't through lack of hygiene or whatever. But it was just through the use of the cushion. As soon as I went onto a Roho cushion it disappeared ninety percent and then when I went onto one of those Jay cushions the scab just went.

(m, 27, 7)

In terms of gender, the incidence of pressure sores was higher amongst males than females (52%:44%) (Table 2.0:288). This probably reflects the generally more active lifestyles of male paras. However, the readmission rate to the Spinal Unit or local hospital for surgery and care was greater for females (66%:44%) (Table 2.2:289). These figures suggest that females get more severe pressure sores than males. However, the higher admission rates for females could equally be explained by a number of social factors including geographic location, medical personnel involved, availability of district nurses, home support, etc.

Unlike pressure areas/sores, urinary tract infection is definitely incorporated into the general health schema of paraplegics.

**Urinary tract infection (UTI): the ongoing saga**

Most paraplegics live with intermittent or continuous, low level bladder infections: the symptoms being cloudy and smelly urine. They do not interfere with day-to-day living but do require the regular intake of fluids (a minimum of one glass of water per hour is recommended) to keep the bladder flushed out and the infection under control and a constant monitoring of the urine (monthly urine analysis is highly recommended). It is this immediacy
of factors which make the incorporation of UTI into the general health schema\(^6\) of paraplegics more reasonable than the dramatic, 'one off' nature of pressure sores. As one para explained:

I'll get a urinary tract at least once a year. But I don't get to the stage where I get the shakes about it. It's that I can smell my urine getting a bit smelly so I'll drink copious amounts of water. But I drink copious amounts of water any way and then I'll go and have a test and they may put me on some pills. And all I have to do is have about 3 or 4 of them and I'm right again. (m,27,7)

However, low level bladder infections can assume dramatic proportions. When a paraplegic begins to feel generally 'grotty' and debilitated, has a persistent headache, experiences aches and pains in the arms, shoulders and back, an increase in spasm and/or sweating, the onset of shivering and rigors, a rise in temperature, or combination thereof, then s/he knows that a full blown UTI has developed and a visit to the doctor is required:

I was sweating like hell all the time and I would feel uncomfortable and wouldn't want to go out because you just sweat profusely and I would lose my appetite and lose weight etc and feel lethargic and feel tired all the time and sort of knock you around. But I used to get them regularly - this was just the worst one. I used to get them regularly and go to the doctors and get some antibiotics. (m,20,4)

The symptoms of UTI can be dramatic, may even be misdiagnosed, and can result in hospitalization:

I was in hospital once for three weeks with a UTI and the temperature's getting up to the forty-one degrees and they didn't know what was wrong with me and it was a UTI ... from then on I took more care. But I still got them. (m,18,5)

Living with chronic UTI is, however, possible even if it does have negative social consequences. As one man (20,4) explained:'I don't feel like doing much anyway. You always feel clammy and sweaty and it makes you feel bad.' Chronic infection can also be very debilitating and disconcerting:

Well, I have always got an infection of some sort and I also think it has affected my blood pressure. My low blood pressure makes me feel quite sluggish so I always feel crook ... sometimes I get cheesed off with it and ...
I just hope that it never gets that bad that it ends up in my kidneys. So I worry a bit ... is it ever going to get to the stage that I will not be able to treat it? (f,23,2)

Perhaps the most compelling reason for paraplegics to maintain a healthy urinary system is that it can be fatal not to. Bladder infections which spread to the kidneys, or the retention of urine and subsequent inflammation of the kidneys, can cause renal failure and death. Until relatively recently, urinary sepsis and renal infections were the major killers of paraplegics. In 1969 I was told that the only medical complication that would kill me as a result of my paraplegia was kidney failure; the paraplegics I interviewed nineteen years later, some who had been discharged from the Spinal Unit for less than a year, had been told the same thing. One reflected on the effect damage to his kidneys had on him:

... last year I actually had some swollen kidneys and that. I've got reflux so I have to make sure I empty my bladder a lot. [Reflex is] Urine going back up into my uretus. Through my uretus into my kidneys, pressure, too much build up of urine in your bladder.... My biggest paranoia are my kidneys. They really bum me out, they really freak me out. Totally terrified of kidney failure. Kills you. (m,19,8)

For most paraplegics, the day-to-day reality is that they learn to live with low level bladder infection. This might mean functioning at just below par but after a while this presents no problems: that's just the way it is, quite normal. It might also mean adopting the strategy of keeping a jar of antibiotics in the refrigerator to which one can turn if the symptoms of impending major infection manifest. Whatever the case, one young para captured the general tenor when he described the few urinary infections he had had as being 'only normal.'

To return to the observation that UTIs are incorporated more readily into the paraplegic health schema than pressure sores, it is useful to look at the nature of the two conditions. To begin with the incidence of UTI was very much higher than pressure sores (72%:50%, Table 2.0:288); the former are more likely to kill than the latter; the state of one's urine is monitored several times throughout the day during micturition (or emptying one's leg bag), pressure points once, at night, if at all; the compulsion to drink regularly is always there and easily achieved. More importantly, UTI conforms more readily to what is conventionally deemed 'ill health'. Apart from the fact that one feels really ill when hit with a full blown

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7 Creek et al. (1987: 3) note that the total mortality rate caused by urinary sepsis for paraplegic patients amongst British Soldiers in the First World War was 80%.
infection and the body cries out for rest, sleep and warmth (conditions best achieved in the sick-bed), UTI is internal to the body. The external manifestations are dramatic (thick, cloudy, foul-smelling urine), the result of biological organisms, and it, the infection, is cured by taking pills, antibiotics. Pressure sores, on the other hand, manifest on the surface of the body, may require surgical intervention but are mostly cured by non-medical means, namely, the relief of pressure. There is no moral dimension to UTI; they are part of rather than a self-inflicted, addition to the paraplegic body. For all of the above factors, UTI fits more easily in the health schema of paraplegics. What both pressure areas and UTI do share in common is, however, a continual refocusing on the body, its contingency, the embodied self. Without the body functioning as completely, healthily, and smoothly as possible, self is kind of cast adrift, wallowing in limbo, unauthentic.

**No joy-ride: pain, root pain, and Harrington rods**

There is nothing quite like pain to focus one's attention on one's body and to disrupt normal everyday activity. It came as a shocking revelation to me that for some paraplegics pain was the overriding feature of their everyday lives. These paras spoke of their lives as not being blighted by their paraplegia, but by the root pain which followed. This pain was variously described as 'like fire burning in my legs' and 'like having tooth ache all over your body below your break'. As one can imagine, it is hard to maintain normal social intercourse, a job, a decent quality of life, or to extract a great deal of enjoyment from living under such circumstances.

It is not just physical pain induced by this syndrome that is so unsettling, but also the psychic pain induced by the perception that the medical authorities do not believe that 'your' pain has a physical cause, is a physical reality. This misperception seems to be the result of poor communication between doctor and patient. Root pain is recorded in the text books as being caused by irritation of the nerves at the site of injury (Hardy and Elsson, 1976:60) but as untreatable. Similarly, the diffuse, ill-defined pain some paraplegics reported is also recorded in the text books. However, this pain could only be treated with increasingly high dosages of powerful analgesics such as morphine and drug addiction was a common side affect before the practice was stopped. This particular type of pain is, however, believed to be caused in part by psychological factors and the treatment now revolves around diverting the patient's attention by keeping them occupied (Hardy & Elsson, 1976:60-1).
One can imagine the doctors’ incredulity when confronted by a complete paraplegic who, by definition, has no feeling below his or her break, complaining about the excruciating pain s/he is experiencing and asking for relief. The doctor, medical science, cannot explain the pain, diagnose the cause and effect a cure. To save professional face the easiest solution is to locate the pain in the patient’s mind. A psychosomatic reaction to the trauma of being paralysed. Yes, that’s it! This person is a malingerer, not prepared to do the work and get on with living. Feels sorry for him/herself. A waste of my time. The following typifies how medical power operated in the Spinal Unit to deny the corporeal reality of those patients with root pain:

While in Spinal Unit initially I complained of unbearable pain - was told to persevere ...was sent home after three and a half months. On my first check I complained again of unbearable pain. Again told to persevere. On next check up I demanded an X-ray to find cause - only to be told further displacement was taking place. Instantly re-admitted [to have] bones fused with Harrington Rods. Pain after some time greatly lessened, but still re-admitted to deaden nerves. (f,36,2.5)

What the ‘experts’ did in this case was to, in effect, call the woman a liar, to dismiss her experience of pain as either a temporary phenomenon or as something entirely of the mind. Fortunately this woman’s reality was eventually vindicated when a physical cause for her pain was eventually detected and attended to. This, however, begs a number of questions: why was she not believed in the first instance and tests carried out? Why the prioritizing of medical scientific accounts of paraplegia over the subjective, corporeal experience? Apart from the frustration of not being believed, the experience must have from time-to-time raised questions in the woman’s mind about the solidity of her body and sanity of mind. Not a comfortable position to be in.

For a number of the paraplegics I spoke to there was nothing mysterious about their pain. It was a consequence of the Harrington rods that had been inserted as a means of support around their lumbar vertebrae where the breaks had occurred. The pain varied from mild discomfort to quite severe. In the latter cases life was markedly interrupted, the little pleasures in life involving physical subtlety such as gardening, could no longer be experienced; according to these paras, the gloss is taken off life and an essential part of being killed off.
**Changed health status: taking body maintenance seriously**

As was mentioned earlier, paraplegia is not an illness to be cured but a chronic condition to be managed. Management typically translates into keeping a close eye on one's health and adopting preventive strategies as a means of maintaining bodily integrity. Before their accidents, health had never really been an issue for the paras I spoke to; by far the majority were active, fit, young (under 30 years), people who were living their bodies to the maximum and who just took their health for granted. Paralysis changed this state of affairs: confronted by one's mortality, corporeal fleshiness, and the body's increased tendency to decay, the paraplegic is forced to take a step back from his/her body, to view it objectively in all its paralysed frailty, and to adopt an instrumentalist approach to maintain the body in as sound a working order as possible. Health becomes a big issue and the formula - health equals life, life equals health - had become the mantra for a number of the paras I encountered.

When asked about post-paralysis attitudes and approaches to health and health care, most respondents talked about how they could no longer take their health for granted. The emphasis is now on maintenance, keeping what remains in good working order and guarding against skin breakdown and UTI. Diet, exercise, and other preventive measures are the most favoured ways of achieving these ends. Diet is crucial for three important reasons: first, since bowel regulation is fraught, keeping a close eye on what goes into the body ensures that waste is excreted at the appointed time with a minimum of fuss; second, a healthy, balanced diet is essential for overall general health; third, body weight is now not just a question of aesthetics, but also one of mobility.

It is interesting to note that the strategies of health adopted were gendered: male paras were more instrumental focusing solely on the physical, whereas females were more likely to adopt an holistic approach incorporating the physical, emotional, and spiritual aspects of being. Notwithstanding, it would be misleading, an ideological romanticism, to give the impression that females were any less instrumental, any less hard-nosed attitudinally when it came to the physical than were males. When speaking of health one woman (22,1.5), reflected how her attitude to her body had changed: ‘...its just a thing really....its like a little machine that does the necessary for keeping you going.’ The onus was on her to maintain that machine in a sound state of repair so that she, the embodied self, might continue to be.

A little over one-third (Table 2.3:289) of all respondents had resorted to alternative or complimentary forms of health in the treatment of conditions attributed to their paraplegia.
One or two were searching for a cure\(^8\), while most were just seeking relief where orthodox medicine had failed. The most commonly used alternative was acupuncture, a form of medicine that has since become virtually orthodox, for the relief of pain. Homeopathy, chiropractic, massage, and colour therapy were other alternatives used. Alternative health care was attractive for a number of reasons, not the least being its relative success and holistic character. For example, some paras had successfully used homeopathic remedies for relief of spasm pain, the treatment of boils on the buttocks (which threatened a massive pressure sore), and in the treatment of bladder infections. In the latter cases, paras wanted to avoid the use of antibiotics because bacteria eventually became resistant to them.

One view of the use of alternative forms of medicine can interpret the practice as resistance to orthodox medical hegemony over the paraplegic body. Orthodox medicine intervenes in the body to cure symptoms of disease, disorder, while alternatives, especially homeopathy, mobilize the body's resources to heal itself. It seemed to me that the use of alternatives by the paras in this study signified a reclamation of the body, a reordering, a reintegration of the body-subject.

When asked to rate their standard of health before and since their accidents, more rated their health as 'excellent' before paralysis than the combined numbers rating 'good', 'very good' or 'excellent' levels of health since their accidents. Even so, two-thirds still reported 'good' or better levels of health as paraplegics with a third experiencing mediocre, 'poor' or 'very poor' health (Table 2.4:289). A high proportion (44%) (Table 2.1:288) had been readmitted to the Spinal Unit or local hospital, the majority being for pressure sore care and surgery followed by urinary tract, kidney, and bladder related conditions (Table 2.2:289).

The paras I spoke to did not, however, judge their general health status and sense of well being solely on the basis of one or two readmissions to hospital for corrective surgery. Judgements were made on a host of factors including the debilitative effects of chronic

\(^8\) These paras belonged to the Spinal Cord Society (SCS), an American based group headed by a paraplegic doctor who is working on a cure which, he argues, is just around the corner. It is the group's belief that resources have been deliberately withheld from research into this area because powerful medical concerns say that repairing a severed spinal cord is beyond current medical technology. In response, the SCS argues that the lack of research reflects the fact that there is more money to be made from treating paraplegics than from curing paraplegia. There might be some truth in this, but it still sounds awfully like a conspiracy theory to me. Nevertheless, the SCS still holds out hope of relief to SCI injured people around the world, especially those with high level quadriplegia and root pain.
urinary infections, pain, heavy sweating, fluctuations in temperature, and susceptibility to ill health. The following quotes from two paras capture the spirit:

I had chronic infection or UTI ... for about a year. I couldn't look at anything objectively because I used to get so ill. I was really negative. (f,22,1.5)

... [Health is generally] Ratshit ... the body is totally run down and rather than a lot of things coming out emotionally, its probably come out in my health ... Heaps of UTIs ... drinking plenty ... on medication. (f,21,1.5)

To close this segment on health status at this point would be to create the totally erroneous impression that paraplegics are generally less healthy than the general population. Indeed, most would argue that they are probably healthier and fitter as a result of their constant monitoring of health. In the context of this segment, health status is taken as relative, as a ‘before’ and ‘after’ paralysis condition. The majority, having adjusted to living a paralysed body, albeit with a few blips along the way, are healthy, fit, active body-subjects who remain so by virtue of the scrutiny they subject their bodies to. The following captures the general tenor of the responses to a question about health status subsequent to paralysis:

My health? Well in terms of diet and that its improved ....

I’m interested in things like, do you get sick? No. My health is maybe deteriorated a little since I have been in a chair ....

Previously you said “excellent”, so now...? Very good. ‘Cos I’ve had two pressure areas ...but I have good skin. Good healing property....I make sure I have a bath twice a day or whatever. Yes.

So you really take care of your body? Yes.

You don’t take it for granted? That’s for sure. (m,27,7)

As indicated in the above, body maintenance had become paramount in the lives of the paras I spoke to. While most carry out this responsibility of their own accord, many indicated that they would welcome some form of institutional support.

Bi-yearly warrant of fitness check-ups please

When asked if they would like to see a structured review system of their health status to be introduced at the Otara Spinal Unit, three-quarters of the respondents were most emphatic that they would. Forty-four percent of those who said they would not, said they would like
to see a medical review system for paraplegics established elsewhere. A number mentioned they had made arrangements to attend such a clinic at the Burwood Spinal Unit in Christchurch and thought a similar review system long overdue at Otara. Others had friends who had been rehabilitated at Burwood, were familiar with Burwood’s system of post discharge care, and spoke enviously of it. One spoke at some length, contrasting the follow up care she had received from Otara with that a friend had received from Burwood:

... even now he gets called down about every two years and hasn’t failed a checkup. And like ... I had sort of forgot about [my first appointment] and then I got asked about 18 months and all he did was lift the back of my shirt up, wack it and that was it; asked me how I was getting on ... when [X] goes back they scan his kidneys they do uridynamics they do everything and every time he goes back they’re comparing his results with the last time that he was in. And they do everything! Like it is like a complete overhaul. So that they can say, "What do your kidneys look like" - they maybe packing out on you and mine [checkup] was just so different. (f,23,2)

This quote captures the general feeling of what a number of paras articulated as the slovenly and off-hand treatment they received when called back to the Otara Spinal Unit for their first check up. It was hardly worth their effort. Rather than the cursory treatment they currently received, they envisaged being readmitted for a few days to undergo a thorough medical assessment. This would include things like a detailed skin examination, a kidney scan, and uridynamics. In addition, a return to the Spinal Unit would also provide the opportunity to 'gen up' on information regarding current physiological research into paraplegia, new techniques and procedures of management, and so on.

At the time of data collection, official thinking at the Otara Spinal Unit was that a paraplegic who they never saw again after discharge was, in a medical sense, successfully rehabilitated⁸. Rather than calling patients back for regular check-ups, the Spinal Unit as 'a resource centre' was the view officially fostered; that is, any para who felt the need should initiate the consultation process. The message is clear: upon discharge ex-residents must take responsibility for their own body maintenance. Which most do, but with the following qualification. During their stay at the Otara Spinal Unit they had impressed upon them the horrors of pressure areas and the life-threatening dangers of kidney infection. Many have subsequently become quite paranoid about skin care, urinary infections, and the state of their

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⁸ At present residents are generally called back within 3 - 6 months to check on their progress. Many complained about the perfunctory way in which this interview and check up was carried out. However, significant changes were planned, including overnight admission for the initial check up so that a series of tests could be carried out.
kidneys. They now hold the Spinal Unit morally responsible to help in the ongoing monitoring of these aspects of their health. A regular review system would provide these people with institutional support and the body security they now seemed to be lacking. This need must, however, be contrasted with those ex-residents who were adamant they would never return to the Unit:

I never went back for any check ups ... I'd heard [the doctor] came round ... and all he'd say is "anything else to report?" and that would be it. No sort of asking leading questions or something because don't know how you're s'posed to feel. You know? Its all new. How are you s'posed to feel? So I wasn't going to go all the way back up there for that. (f,21,1.5)

Up to this point the most obvious feature of the paraplegic body - paralysis, motor impairment - has not been addressed. This is not to say that not being able to walk is inconsequential, but, rather, highlights the fact that this aspect of paraplegia was generally regarded as the least problematic corporeally. The inability to walk is most telling within the social arena and will be discussed in greater depth in later chapters. At this point, the way motor impairment was addressed at the Otara Spinal Unit and the implication for subjectivity will be examined.

TREATING MOTOR IMPAIRMENT: TOTALIZING ASPECTS

A theme frequently returned to by the paraplegics I spoke to was the totalizing approach adopted at the Otara Spinal Unit. Firstly, they believed that as patients they were seen totally in terms of their paralysed bodies: programmes were overwhelmingly directed at building up the normal innervated, non-paralysed parts of their bodies to compensate for those parts which were now paralysed. This, almost total, emphasis on the body/physical was carried out at the expense of the emotional and psychological. A woman commented:

... they do not sit down and talk to you and see what you're thinking ... I use to fight with him [physiotherapist] and they use to say "you should enjoy going to physio. You should want to get on." But I said I needed time to myself, but they would not give that time for mental health, psych yourself up for whatever is ahead of you .... You're not a person, you're a number. (f,21,1.5)

Subjecting all patients to the same rehabilitation programme, regardless of individual needs, compounded the impression that the physical was more important than the psychological:
... a set programme for all patients regardless of fitness, tiredness, age etc...
I can remember an elderly man who was finding the programme exhausting - surely a rest time ... would have been appropriate ... one afternoon when my back was giving me hell, I had a headache and was really tired out, although I was positive about physio etc., I was not allowed a rest, let alone a short sleep in the afternoon. (f,36,2.5)

I didn't mind the routine it was the attitude. They weren't patient enough with every individual person's body. (m,20,2)

Another totalizing aspect of treating motor impairment was the appeal to remote paraplegic bodies in medical text books and using these archetypes as the measure of their bodies, of what they were capable of doing, and of them as people. In short, standard, text-book procedures and goals were rigidly adhered to allowing little deviation from the 'ideal'. Inevitably, some paras felt as if they had been sold short in terms of the recovery they might have achieved, or had been labelled as 'no hoppers' who had not reached their full potential as prescribed in the text books:

... instead of treating you like an adult, an individual person, you are just number six, room ten. OK, it is his time to shit, it is his time to piss, put him in his chair, feed him, and get him the hell out of here....[when] everyone is different, every person is different, every accident is different. No two accidents are the same but if you are a L3 para then OK, there is your break and all other L3 paras can do this, and that is it. If you can't do that then what the hell is wrong with you? (m,30,8)

One of the most deeply personal ways in which many felt as if they were having their sense of individuality removed was in the imposition of a universal programme of bowel and bladder management: everyone was expected to move their bowels first thing, every second morning regardless of their pre-paralysis routine. The standardization of bowel evacuations may well have contributed to the convenient management of the Spinal Unit, but the subliminal message was that individuals were now part of an homogenized, paraplegic population.

A message of the same order was discerned from the general lack of respect for patients' privacy. This was particularly so for female patients where bladder training was not always handled with care and sensitivity: '...its another body. And because they are so used to it, they expect you to be used to it too' (f,21,1.5). Under these conditions it was not surprising that many felt that they were being treated like numbers, being normalized as 'cripples', as 'paraplegics' rather than as individual subjects.
The impersonal and seemingly arbitrary application disciplinary body techniques compounded the effects of motor and sensory impairment to induce important changes in self-perception. First, the concretization of what Foucault (1980) calls the power/knowledge nexus and the realization of the disempowering effects of paralysis: spinal unit staff have the knowledge about paraplegia and are in a position to do things to my body and to me. Patients who were already feeling confused, threatened, and powerless by their paralysis were made to feel even more powerless by the arbitrary imposition of regimes of treatment which took no account of their individuality and individual needs. In this process their sense of 'self' was challenged, called into question as they were redefined totally in terms of the(ir) paralysed body and socialized into becoming 'paraplegic'. A number spoke of feeling like their bodies were the raw material in a factory process devoted to churning out 'rehabilitated paras', that is, productive paraplegic bodies. Second, the 'objectification' of the body which began with the manual self-care the body now demanded was compounded by the rehabilitation process. The production line techniques, the loss of privacy and, frequently, the sense of personal dignity that privacy ensures, the lack of meaningful consultation with the health care professionals, and the lack of individuation - all contributed to the individual's sense of loss of subjectivity, ownership and control over his or her body. In this process the body becomes 'object' which largely determines what, when, and how an individual does things with his or her life:

You know I said my body was an object now, the primary reason is the treatment I got in the Spinal Unit. (f,22,1.5)

While this perception/judgement of the Unit, and its staff, may seem a little harsh, it is ultimately correct. However, it may also reflect the unrealistic expectations patients had at the time about what could be achieved, in terms of rehabilitation, within an institutional setting. Not all contingencies can be covered and, as will be demonstrated in the next chapter, a variety of problematic attitudes and situations are bound to be encountered out in the real 'world'. These can not be realistically simulated within the Spinal Unit because of the time factor. The real expertise of the Spinal Unit lies in training nascent paraplegics in techniques of body maintenance.

It would be wrong to conclude this section and leave the impression that once inside the Otara Spinal Unit patients became totally quiescent and accepted uncritically normalizing medical expertise. In many cases the memories of former idiosyncratic, non-paralysed
bodies provided a reference point from which to resist. For example, a male talking about his resistance to the imposition of impersonal regimes of bowel and bladder management:

You are going to go to the toilet every three days...that is what is in the book and that is what you are going to do....I said, "Like hell. I go everyday. This is the way that I went before my accident, why should I change now?"....And you have got to use a catheter [to empty the bladder] and you have got to this and that and its all a load of crap because when I got outside ...I just threw them all away and just use a uritip. (m,30,8)

It is evident that such resistance is as much about the rejection of authoritianism as about stating corporeal ownership, of reclaiming back one's body, of feeling comfortable with one's corporeality, asserting one's own authority over one's own body. This is not to say that all medical expertise was rejected. Rather, that only the totalizing aspects were strongly resisted, while the positive, productive aspects were assimilated as necessary, life-enhancing techniques.

Finally, while it is obvious that any rehabilitation of the motor impaired, paraplegic body will involve concentrated physiotherapy aimed at building up the upper body, chest, and arms, it was the almost total emphasis on the restoration of physical mobility which riled the majority of paraplegics who spoke to me. Some believed that this was aimed at turning them into particular subjects, 'one of them,' a fear clearly expressed by a younger male:

...all they do is give you physiotherapy, teach you how to dress yourself and do transfers. Its like they are trying to turn you into a cripple. (m,18,5)

SUMMARY AND CONCLUSION: THE PARAPLEGIC BODY-SUBJECT

In this chapter the ontology of the paraplegic body has been examined by focusing specifically on the physical and medical implications of paraplegia. The paraplegic body is a whole new experience characterized by contingency and technique (wet/dry, clean/dirty, clear/cloudy); the reality of the embodied self becomes more immediate and concrete as various bodily functions go off-line, or cease to register as the autonomic system closes down; survival becomes a matter of conscious monitoring and body-care technique. Paradoxically, for the self to remain healthily and functionally embodied it must become, in a sense, disembodied as self cares for the body as vulnerable object. It is these hidden factors, the contingencies and programmes of care, that make the lived experience of the
paraplegic body so different, which govern life and influence self-perception more so than the glaringly obvious inability to walk. Hence, rehabilitation, the term conventionally used to describe what goes on at the Otara Spinal Unit does not fit comfortably with what is really happening. Re-embodiment of self seems far more appropriate because the subject is being taught how to live a new body, a paralysed body, productively. A body which will dominate the subject’s life in ways that were inconceivable before paralysis.

The chapter closes with three paraplegics talking about how living their paraplegic-bodies has changed the way they live their lives and the way in which they perceive self. The first quote is from a male, paralysed for twelve years:

You gotta look after yourself. I don’t think about it all the time, but you gotta be aware of pressure areas and things that may go awry. I suppose you become more aware. Yes, I mean since I’ve been in the chair I’ve become more aware of the body, what it can tell me and what it can’t tell me, you know? I just don’t take it for granted. If something goes wrong, maybe get some spasm, it’ll tell you. (m,22,12)

While this paraplegic’s sense of being is not overly dominated by his paraplegia, he is always aware of his body, it’s special needs and adjusts accordingly. After twelve years, living the paraplegic-body has become quite natural. Indeed, it even tells you when things are going wrong.

Gordon, paralysed for eight years, is gregarious, somewhat opinionated but likeable. However, the confidence and control he exudes is underpinned by a disciplined and conscious monitoring of the body:

I think of my body as a baby now and I’m the mummy. In my brain I have to think about and worry about it. How I’m sitting ... I have to think for my bodily functions, when I go to the toilet. What time I do it, how often, whether or not I’m sitting on an object and getting a pressure area. I worry about my kidneys. Drinking fluid, you know. I just generally am in tune with my body. I know more about my body than most people would about theirs. I know all about the parts. I know how it works.

He has to know more about his body precisely because it does not work. And it is in that lack of function that he forges identity:

... it’s a bit of a drag really. I hate - it’s always a time for a reflection on the fact that you’re a cripple. It’s a constant reminder that you are paralysed because otherwise you just wake up in the morning and jump in your wheelchair and it really doesn’t matter that you’re in a wheelchair or not. You don’t
even look at it ... I don't ... It's not until I have to, say, be in a pub, I've got to go and pass a catheter or go and have a piss or a shit and you've got to do it all in a certain way. You've got to have sterile, clean conditions and it starts to manipulate your life. Your body dictates to you and it's always a reminder that you are different. Those are the things that keep you different otherwise if you didn't have any bodily things wrong with you and you had all your bodily functions, pissing and shitting and coming [ ejaculate] and you were in a wheelchair, really, in the end it would make no difference that you couldn't walk. (m,19,8)

Mary has been paralysed for four years. She begins by talking about the changed appearances of her body, first in comparison to how it used to look, now, how it compares visually to other female bodies, and finally, she evaluates it as a sexual object. She then goes on to speak about how the physical effects of paraplegia influence the way she perceives her body-self:

... [I was] Proud of it. Very ... when people keep telling you, you have a good body ... you believe them after a while. They were right. But it made me look back, and maybe in hindsight it just seemed so neat because ... you have lost so much now that maybe it wasn't that - but it must have been because I did modelling and that sort of thing. It was better than normal ... I am not so proud of it [now] ... I am not so positive about it ... things don't look the same any more. She's a bit chopped about with cuts here and there and scars ... it is not as appealing, physically ... I do feel less attractive ... there are some worse people around. But when you get up in the morning and the shower chair and everything is paralysed and its all just hanging there and you look in the mirror on the way past and there's this body sitting in a chair and paralysed boobs and this and that and you think, "Christ this is me. Imagine anyone else looking at that and finding it appealing."... Little things that you took for granted now are big things ... I would just like to be a bit more normal. I don't mind having to sit here if that was all it was is. If I could just sit here without the pain up my bum and this sweating all over the place ... and you didn't have wee problems and pooh every now and then and you could do that. (f,23,4)

Clearly, she feels physically, personally and socially devalued. She knows that all bodies, especially female bodies, are valued socially for their physical appearances. Moreover, judgements are made on the basis of physical appearances and perceived 'able-bodiedness' which impact on things like employment and career opportunities, income, relationships and so on. These are some of the issues addressed in Chapters VII and VIII which focus upon the social location and interpretations of the paraplegic body-subject when s/he ventures out into society. The theme of corporeality continues in the next chapter with the exploration of the boundaries, nature, and geography of the paraplegic body.
To the casual observer the most obvious thing about people in wheelchairs is that they cannot walk. However, for the paraplegics I spoke to, not being able to walk was the least problematic aspect of paraplegia for them. This is not to say that having to use a wheelchair was a minor inconvenience, rather that the associated body maintenance and social prejudice were far more onerous. Notwithstanding, the inability to walk and having to use a wheelchair does have important implications for the paraplegic body. First, it's spatial dimensions change. It is bounded differently and, like the eight month old baby who acquires the specular image (see pp.20-21), a new body gestalt is established which involves a kind of alienation as 'there is a conflict between the me as I feel myself and the me as I see myself or as others see me' (Merleau-Ponty, 1963:137). Second, the paraplegic body's physical geography changes by virtue of the incorporation of a wheelchair for purposes of mobility: it can no longer traverse the same physical terrain independently. Third, because it is anchored at a different point in space, its 'geometrical distances which stand between myself and all things' (Merleau-Ponty, 1962:286) are radically changed. The implications of this are that the paraplegic body-subject is limited in terms of what it can reach out and touch and do. More importantly, it follows that the social geography of the paraplegic body also alters radically: it occupies and is assigned different social space. How these changes might impact on the ways self is constituted are explored in the first part of this chapter. The chapter concludes with a consideration of the fundamental questions raised about the nature of the paraplegic body by its changed interoceptivity, by its loss of tactile sensation, and by the gain of involuntary muscle spasm.

ESTABLISHING NEW BOUNDARIES: MOVEMENT, MOBILITY, SPACE

*Mobility as opposed to movement*

The first four to six weeks in the Spinal Unit are spent sandwiched in an especially designed bed, a Stryker frame, which immobilizes the body and the spine to allow the fractured

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1 Merleau-Ponty (1962) placed considerable importance on the relationship between the spatial dimensions of the body and subjectivity. His argument is outlined on pp.16-17.
vertebrae to heal. Every two hours the Stryker frame is flipped in order to change the pressure on the skin and to prevent pressure sores. There is never any doubt about one's status as a body, but a whole series of questions about self, about who and what one will become, are raised. More importantly, the 'how' questions ask: how will I do this? how will I do that with a body which I cannot move, which I cannot feel? Sometimes, adding to the confusion, phantom feeling is experienced in the lower limbs which, like a sink emptying, gradually drains away. Given the enforced, immobilization of bed rest the significance of bowel and bladder dysfunction cannot be fully appreciated while the significance of not being able to walk is perhaps over-estimated. Under such conditions the body and the spaces it might occupy seem to shrink. One man remembers his feelings as he lay recovering from serious injuries sustained in a motor accident:

When I was in bed I thought shit! I'm never going to play rugby again. I'm never going to run again. All these sports that I played ... running ... rugby and basketball ... athlet[ics] ... I thought I can't move ... all I'm going to do is just lie here. Lie here till I die! (m,15,10)

This captures the horror of the adolescent's realization that he was never going to walk again; that whole areas of experience were now denied his being; life suddenly looked very bleak. Happily things turned out differently for this person who went on to represent New Zealand at various Para Olympics and Commonwealth Games. The turning point came when mobility was restored to his body. Mobility, not organic movement. Mobility in the form of a wheelchair; technological mobility as opposed to the natural movement of walking that is produced by the expansion and contraction of muscle groups in the legs.

Technologically induced mobility is, in many ways, an inferior substitute for natural movement simply because of the limitations imposed by the technology. For example, a body-subject in a wheelchair cannot freely negotiate a set of stairs, undertake a bush walk, access all the living spaces that an upright and ambulant body can. So mechanical mobility as opposed to natural, organic movement is deliberate, careful, planned. And while many of the paraplegics I spoke to nominated the loss of spontaneity of movement as the worst aspect of paraplegia, reflection upon the wheelchair-paraplegic body-subject relationship does reveal an organic unity. Especially when carried out in the light of Merleau-Ponty's work on the corporeal schema and what paraplegics had to say about their wheelchairs.
The organic link: paraplegic body and wheelchair

At first the wheelchair is very much a foreign body; a piece of technology which, more often than not, the body violently rejects at first sitting:

...because you have been lying down that long they finally sit you up and all the blood goes out of your head and you are either sick or you faint and I couldn't feel the wheelchair that I was sitting in. And it was the worse feeling that I have ever felt in my life ....they just threw me in this big wheelchair ....I was hanging onto these things on the side and they thought I could feel them but it was a low backed chair ...[and] because I was stuck with a high break I couldn't feel that I was sitting in the chair....It was a horrible feeling. (m,21,3)

The body has to grow into the chair, to extend the body image and incorporate it in the corporeal schema as an organic part of the body. This occurs in a relatively short time as the body gets use to sitting up, finds its centre of gravity and point of balance. The more the paraplegic uses the chair the more it becomes an integral part of the body. As the corporeal schema expands to incorporate the wheelchair, corporeal boundaries change and the body assumes a different shape. The proprioceptive body image alters accordingly so that one's new dimensions, spatial arrangements, positioning, and location, are simply known; it is not necessary to measure the doorway or the gap between cars in the car park and then to mechanically check that against that of the wheelchair, the paraplegic just knows (to very fine tolerances) if s/he is going to get through. At this point the wheelchair has ceased to be mechanically linked, a mere appendage of the paraplegic body. Rather, the wheelchair has become organically articulated with, a part of, the 'paraplegic' body.

Mastering the chair has many similarities with learning to walk. Just like the toddler who has many falls as it is learning to string a series of steps together, the para who had yet to fall out of the chair backwards and then get back in by his/herself is not considered a 'real' para by his or her peers. Falling out backwards usually occurred while learning to wheel-stand. Wheel-standing is crucial for getting up and down roadside curbs. It involves flipping the front castors up and balancing on the two back wheels. In this manner a single step can be negotiated by placing the front castors on the top of the step or curb and then by leaning forward and pushing the rear wheels up onto the step or curb. This is rather a precarious manoeuvre. Initially, it frequently results in backward flips and the problem of getting back into chair without the help of anyone else. This constitutes an initiation into the world of true 'parahood'; it signifies true independence, an institutionalized rite of passage from the Spinal Unit. After a few 'curb-jumps', the whole exercise becomes second nature, is achieved without thinking in one fluid, organic, motion of body and chair.
The wheelchair and bodily integrity

That the wheelchair and paraplegic body have become one corporeal whole is born out by the singular attitude paraplegics had with regard to people touching their chairs. This is particularly so when the stranger lends a 'helping' hand by, for example, pushing the chair without first asking, or by insisting on helping one get one's chair into the car. In the first instance the reaction is often violent for a number of reasons. It endangers bodily safety as the sudden and unexpected application of extra motive force can upset balance, tipping the paraplegic out of the chair. More importantly, it is about establishing corporeal hierarchies, the wresting of control over his or her space and being from the paraplegic. But it goes far deeper than this for it is ultimately about bodily invasion, touching 'me', common assault. As one para explained:

Nothing pisses me off more than when some stranger just comes up and starts pushing me around. It's a real invasion and I generally abuse the shit out of them.... (m,19,8)

Even when permission is given to someone to push, the results are predictable: cracks in the pavement, ruts in the field, roadside curbs are suddenly fraught with danger because the pusher must negotiate them mechanically; the negotiations can be clumsy and exaggerated, markedly increasing the risks of separating body and chair. Or getting pushed through a crowd is even more painful - both for self and others; the person getting pushed must continually apologise for his/her presence as ankles are hit, toes run over. The pusher simply cannot judge distances. S/he has a mechanical relationship with the chair. Left to his or her own resources, the paraplegic can usually negotiate the outdoors and crowded spaces quite successfully: the corporeal schema envelopes both body and chair creating an organic whole. Distances, dips, and gradients are known, understood, and negotiated fluidly.

Some paras spoke of the sense of unease they experience when separated from their chairs. When in bed it was essential that their chairs remain besides them within easy reach, their chairs had to accompany them wherever they went, even on a Sunday drive with others, 'without my chair I am without my legs'. To these paraplegics the[ir] wheelchair is body, mobility, freedom, independence. Literally and figuratively.

Clearly then, the wheelchair is much more to the paraplegic than just a metal frame, seating and wheels. It extends the paraplegic body organically and increases its productivity in the same way that organ transplants increase the productivity of sick bodies. The associated
technologies of cushions and, for males, external catheters similarly extend the boundaries and productivity of the paraplegic body. This is particularly so of the cushions which use silicon pads to simulate body tissue as a preventive measure against decubitus ulcers. In the meantime, muscle spasm and the loss of tactile sensation call into question the nature of the paraplegic body.

INTEROCEPTIVE ASPECTS OF THE PARAPLEGIC BODY

Closely associated with the loss of motor function is the loss of tactile sensory perception and, for some paraplegics, the gain of involuntary muscle spasm. The health implications of the loss of tactile sensation have already been canvassed as have the consequences for subjectivity. But this changed interoceptivity does raise some fundamental questions about the nature of the paraplegic body.

*Muscle spasm without tactile sensation: restoring cænesthesia?*

For many paraplegics the most telling sign that the paraplegic body is an unruly body is, perhaps, the uncontrollable muscle spasm that returns over a period of months to the trunk and legs. Spasm can range from being a blessing to a curse. Gentle to moderate spasm slows down the rate of muscle wastage, maintains body tone, facilitates blood circulation, and helps in the prevention of pressure areas. At the other extreme it intrudes violently, limiting experience and simple joys:

> I'm just useless at wheeling because immediately my legs just go rigid and I start to fall out of my chair. So about every five paces or so I have to stop and get my legs down ... if I don't tie my legs down I just go "flop" [and fall] right out. (f,22,1.5)

Imagine the frustration born out of not been able to wheel around the road for exercise, go down to the local dairy, to go for a simple stroll with a friend in the evening, and so on. Other paras experience of spasm fell somewhere between the two extremes, as captured in the following quotes:

> ... its a bit of an embarrassment at times. Like when you're out shopping and your leg suddenly shoots out straight in front of you and all your shopping falls off your lap. (f,26,10)
I can’t … lift my legs up… I find I am fighting against muscle spasms and it is really hard. (m,21,2)

… it’s a general piss-off: feet jumping around off the footplates and that, gut spasm, back spasm throwing you back, you know. It really gets to me at times though - like when you’re trying to get your legs into your trou and spasm locks them up and you can’t do nothing until it dies down. Or like when you’re getting into the car: you throw your legs in and they jump out. A real bummer … [but] That’s the way it is, you just have to get on with it. (m,17,10)

A note of fatalism is detectible in both these quotes; a reluctant acceptance of the perverse nature of the paraplegic body; a body of which parts conspires against one’s best intentions. Perverse insofar as it is impossible to move the legs by an act of will yet they are full of uncontrolled and uncontrollable movement: they move in the opposite direction to where the subject wants to place them, they feel heavier and require more energy to move. The legs’ uncontrollable, spastic movement compounds the sense of curiosity and alienation the subject may already feel towards his or her paralysed body.

For some paraplegics there is a curious aspect to spasm: it restores a sense of ‘feeling’ to the paralysed body making it simultaneously more and less knowable. ‘Feeling’ does not quite capture the sensation; a brooding sense of interiority and presence is more accurate. Spasm seems to operate to partly restore the cenesthetic aspect of the body’s interoceptivity. That is, the subject ‘feels’ internal sensations, the leg muscles working internally, pressure on the abdominal organs, while not perceiving any tactile sensation on the outer skin. In turn, the sensation of the movement that is going on in the paralysed regions is transmitted to the non-paralysed body by way of the outer skin and internal muscle sheaths that traverse the paralysed-non-paralysed divide: a curious sense of feeling the non-feeling. This was not just limited to paras with spasm. A number who did not get spasm commented on their ability to ‘feel’ inner sensation.

There are three other aspects to the loss of tactile sensory perception which reveal more of the paraplegic body’s curious and alien nature. First, there is that which corresponds to what Merleau-Ponty calls ‘the dead weight of the body’ and to which I have referred to as a ‘brooding presence’. For those with spasm this feature is more obvious as the muscles may always be in a state of tension which is then transmitted to the sensual body. One’s legs ‘feel’ heavy; you just ‘know’ that they are there. Moreover, they act like a keel keeping the rest of the body upright, balanced.
Second, the other interesting feature of sensory loss is the impression gained from touching and feeling a non-feeling part of your body. It is really quite a weird feeling. Like its not your leg or its not your stomach when all the time you know that it is 'my leg', that it is 'my stomach' that is not responding sensorially to my touch, that refuses to acknowledge me. At this particular moment the nature of the paralysed body is revealed as different, alien, belonging but not belonging.

Three, the disconnectedness one feels with one's body combined with the loss of motor function lends weight to Descartes' mind/body dualism. The subject is, indeed, trapped in an unruly, eminently fleshy paraplegic body-prison: paraplegics spoke not so much about 'my body' but overwhelmingly in the third person about 'the body,' indicating a sharp distinction between mind and body.

It is obvious from foregoing that the paraplegic body is by nature paradoxical, mysterious. Its apparent completeness, unchanged external appearances, and freely willed movement is opposed by the reality of its changed and extended corporeal boundaries, its loss of external sensation, the compensatory gain of a fuzzy interiority, loss of movement and, in some cases, gain of involuntary and uncontrollable movement. While the paraplegic body may be beset with internal division, its redeeming feature is that it is complete, whole:

I like having, like to think that my body is still all there. Rather than minus an arm or minus a leg ....appearances play a big part. (m,22,7)

Whole or not, the paraplegic body is limited in terms of where it can go in a wheelchair. Having established that the boundaries to the paraplegic body are extended to include the wheelchair, it is logical to say that the paraplegic body assumes a radically different shape to the non-paraplegic body, is located differently in space, has a different physical geography, and occupies different social space.

THE PHYSICAL AND SOCIAL GEOGRAPHY OF THE PARAPLEGIC BODY

The issues to be covered in this section are more commonly written about under the heading 'Access'. The effect of this is to remove or place the body peripherally in the debate. The focus shifts to making a place or situation technologically accessible in terms of wheelchair access, the provision of hearing loops, braille, audio tapes etc. Since this thesis argues that
the paraplegic body is corporeally quite different from non-disabled bodies, that its boundaries have changed to include and make an organic connection with the wheelchair it would be inconsistent to treat access as if it were disconnected from the body. It follows that a particular geography is inherent to the paraplegic body precisely because the body is paralysed. There are two aspects to this geography - the physical and the social. First, all paraplegics are limited in the same ways by the physical environment (natural and built). The 'where' and 'how' they go, is now vastly restricted and consequently quite different to where they used to go and be. Similarly, as paraplegics they inhabit a social world that is irrevocably changed as they are now anchored quite differently in space. In turn, this alters social interactions because the spatial relationship assumes a different quality altering the conditions of intersubjectivity.

**Why social and physical geography?**

Given that reference has already been made, and will continue to be made to Merleau-Ponty's 1962 work on the geometrical dimensions of the body, the use of the terms 'physical geography' and 'social geography' may be confusing. However, they have been chosen in the light of Norbert Elias's *The Civilising Process* (1978) and *The Court Society* (1983) (see above pp.35-36). Here Elias argues for the 'sociogenesis' of a particular subjectivity, the courtier, within a specific geographic space, the court. *Mutatis mutandis*, the paraplegic body occupies a specific geographic space, hence a particular physical and social geography obtains for the paraplegic body. The question remains as to the effects of these geographies on subjectivity, on the way the paraplegic constitutes self?

**PHYSICAL GEOGRAPHY**

There are three moments where/when physical geography effects a sense of alienation on the paraplegic body-subject: the home, public buildings, the natural environment.

**Home and surroundings**

While the body is being rehabilitated at the Spinal Unit, the dwelling to which it will be discharged should also be undergoing a similar process: ramps added, doors widened, kitchen altered, bathroom and toilet modified. On the approval of an occupational therapist judge, Accident Compensation Commission (ACC) will approve and pay for necessary alterations. For many paras the process was completed on time and with minimal disruption to peace of mind. However, for a sizable minority the process was a nightmare from start to finish. Fundamental disagreements over what alterations should and should not be done
with officious, petty-bureaucrats frequently resulted in delays and ill feelings towards self, situation, and ACC. Some alterations were just not done. In the following cases the old adage that 'a man's home is his castle' does not apply. Rather, 'home was hell' seems far more apposite:

It was a year before the ACC did the alterations ... I couldn't get outside or even go into the wash house to do the washing ... I couldn't get into the toilet ... I used to do all my personal cares ... with a bucket.... My family had to ... empty things for me. I was dependant on them for that the whole year ... I got depressed a lot.... It was terrible sort of falling back on somebody to do these things for you ... they didn't like it either. (f,44,8)

Another para was sent home to live in a cabin which ACC had hired and put on his parents' remote, seaside property:

... within two days ... I felt like knocking myself on the head because I couldn't even get out ... onto the grass ... I was there for a year and I couldn't even get to the toilet - just a five gallon drum in the bedroom.... To have a shower I used to have to get carried up the stairs. The old man is sixty and my mother is fifty-nine ... so I had to get my mates from down in the Bay which meant that if they went out fishing for three days, then I didn't have a shower for three days. (m,21,2)

This mismatching of body and environment had consequences for both body and self. Given the crude toileting facilities it was not long before he cut himself and developed pressure sores. These, combined with the inaccessibility of the house, induced a sense of worthlessness in self: '...you feel that you are just useless. I felt that I was just a big burden on everybody.'2 The solution was for this para to design and build his own home (which he was doing at the time of the interview). He was careful to add, however, that while the house was 'designed around a wheelchair' it did not look 'out of place ... like a handicapped house' (m,21,2).

What he means by 'a handicapped house' is immediately understandable to all paraplegics. *Handicap* is a word loaded with negative meaning for all disabled people as it implies dependence and becoming the object of charity. The trick is to blend the architecture of the house with that of surrounding dwellings: externally avoid ramps with heavy, obvious handrails, internally avoid the hoists over the bath, an excess of handrails around the toilet

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2 Another interpretation of these events is presented below on pp.200-1.
etc. Be architecturally discreet for, as one para observed, '...special facilities [are] a constant visual reminder' (m,37,9.5) of who and what one is.

Getting about and doing
Physical geography determines where one can go. This ultimately determines what one does and with whom one does it. This has implications for the way one constitutes self:

Well I don't really talk with my old man and that ... at the start ... we used to be like brothers ... we've grown further apart now because ...[he] See[s] a lot more of my brothers ... play[s] golf with them ... pisses me off [as]... All I can do is go to the pub and play pool ... when they go and play golf and things like that. (m,15,10)

Reading between the lines, it is obvious that this para is both saddened and resentful that his relationship with his father has entered a period of decline. The physical geography of his paraplegia denies him access to his father at play, the right to know his father as an adult, to develop a man-to-man relationship with his father, to critically explore his role-model of masculinity3. At a more fundamental, cosmological level there is a weakening, severing almost, of the immediate link with his whakapapa, his genealogy, which locates this Polynesian in time and defines who he is in relation to whanau (family) and iwi (tribe).

At the other end of the spectrum, physical geography conspires to bring couples together, to constitute self in relation to another in a productive way, even if there is a sting in the tail:

... when the world lets me, I get into it. But obviously, it's easier when you've got a partner that's able.... We've done lots of things ... because ... Brian can lift me. But I can't be as independent as I would like to be. (f,26,10)

There is also another dimension to the constitution of self which is linked directly to the physical geography of the paraplegic wheelchair-body-subject. That is the way in which the world adheres to and touches the body:

I don't ... consciously think about it [being paralysed].... Until ... there are things that piss you off ... like you go outside and get mud all over your ... wheels and then it's all over your bloody clothes. Like you can't go out there and do gardening like you'd want to ... I'm just pissed off that it's happening .... (m,19,12)

3 Recent texts on masculinity stress the importance of the father/son relationship to the process whereby boys/men constitute themselves as masculine. Later in life this may involve seeking relationship with formally absent fathers or a reassessment of their masculinity born out of the 'manly' things they did with their fathers throughout their boyhood.
In a sense, this paraplegic is reflecting upon the specific type of subjectivity generated by paralysis, on what it is to be a paraplegic in terms of grubbiness, uncleanliness. Consider the wheelchair-body-subject wheeling down the road and what s/he might pick-up and transfer to the person: dog excrement, vomit, spittle, rotting organic material, etc. It is all part of being a paraplegic. A sort of fatalistic stoicism sets in about doing and being: few resort to wearing gloves.

Most paras spoke about their changed geometric/spatial relationship with the world in terms of not being able to reach things. One, however, spoke at some length on this subject, couching his discussion in terms of how his perception of the world had changed since getting paralysed and how these perceptual differences changed his consciousness of objects in the world:

Paraplegia has changed the way I think. Totally...you see things at a higher level when you're able-bodied than when you're paraplegic...the level that a paraplegic sees it is ....Different from an able-bodied ...we get exactly the same view, but we see things completely different....[Giving] Completely different meanings to things....[Such as] Going into shops...wheeling through shelves. You don't realise how wide [narrow] they are till you're going down them in a wheelchair.... And how awkward things are out of your reach. And how hard it is to read labels when you are kinda too far back. (m,20,2)

This paraplegic's geometric relationship with the world has changed and with it the meaning of objects in the world. This confirms Merleau-Ponty's (1962) contention that one's relationship with things in the world in terms of a 'lived distance' has important consequences for psychological being, for consciousness, and self. As with inanimate objects, so to are social interactions altered by virtue of the changed spatial relationship that now obtain between the paraplegic body and non-paralysed bodies.

SOCIAL GEOGRAPHY

Social geography comes into play in a variety of situations from one-on-one meetings to larger social gatherings.

Intersubjectivity

When discussing intersubjectivity earlier, rejection at the corporeal schema level has been proposed as an explanation as to why former friends, acquaintances, and strangers acted in such an apparently irrational way to the paraplegic body-subject. There is, however,
another factor which colours and shapes all interactions between paraplegics and non-paraplegics, namely, the spatial dimensions that obtain on these occasions. A new social geography emerges in which the paraplegic body, always sitting, perceives the world differently, and the world touches the paraplegic differently.

Making contact with old friends, relatives, and acquaintance for the first time as a paraplegic can be fraught. Both sides are second guessing the other as to what the outcome might be: how should we behave? how will they react to me? should we talk about yesterday's rugby match? how will we get her into the house? I hope they don't make a fuss. Where will we put him? It can be a very tense situation for all involved:

... aunts and people that I had seen in the actual Spinal Unit when I was in bed. I can always remember the first time...thinking, 'God I have got to wheel into that room and they haven't seen me in a wheelchair.' It was always a bit nerve racking ...even now ...I would still be aware of the fact that they had never seen me in a wheelchair before. (f,23,4)

The underlying fear is that the 'aunts and people' who saw her as 'Mary' when she was lying paralysed in the Spinal Unit, looking just like 'Mary' in bed, would see and experience her quite differently when they saw her in all her paralysis, in her tainted wheelchair space. Space which is largely defined by the iconic wheelchair which reeks of dependence, decrepitude, decay. The presentation of self in a wheelchair to others who have only ever known you as 'normal' is 'nerve racking' precisely because the text which they formally read as you no longer follows the same story line. It looks the same but it is sitting down, unmoving, inert, paralysed. A new body gestalt has been established in which the view others get of the me is in conflict with the me which the nascent paraplegic feels him or herself to be. The fear is that 'aunts and people' will either a) reject the 'wheelchair bound' subject out of hand or b) coddle by imposing a stereotyped, 'tragic victim', disabled subjectivity on their child/friend. Two paras, initially responded to as 'tragic victims', recall in writing the impact this had on them and their subsequent reactions:

Pity [from family] at first, now respect....I was knocked back, got depressed.
I had to try harder. I suppose this made me stronger. (m,21,10)

For this para, the imposed stereotyped view is quiescently internalized. The solution is for him to change himself in an attempt to change other's perceptions of himself. It seemed to have worked because his family and friends now treat him with 'respect'. It is not possible to tell whether or not the subject had initially adopted and acted in accordance with the
stereotype but this is a probability. The family's behaviour may well have been determined by a reading of the disabled subject, not their paralysed son/brother. In the next instance, the opposite occurs:

Family - fed with bullshit from the spinal unit, so uneasy. Friends - shocked and most couldn't handle it. Sorted it out with family - all have adjusted. Friends - one I keep in contact with. The rest drifted away quickly. Only my family mattered ... it was hell being a paraplegic - other people had to like it or lump it ... Now I don't care what anyone thinks about me. I am me; I'm not out to please people just because I'm in a wheelchair. After seven years you get hardened beyond belief. ANGER! (emphasis in original, m,23,7)

Some background information helps situate this response. The paraplegic in question holds himself totally responsible for his paralysis: he rolled his car when taking a corner; a constant source of frustration. Moreover, he suffers root pain. Given his own pain and anger, it is of little wonder that this man refuses to expend time and energy in changing the stereotyped view others, apart from his family, might hold of him. He was/is too busy dealing with his paraplegia. Indeed, today, seven years on, he still hangs onto his anger like a crucifix. A miasma of deep psychic and physical pain and anger hangs about this paraplegic; the image of a deeply embittered subject cannot help but emerge.

This is in sharp contrast with the many other paras who also recalled having to 'sort out' family and friends who initially reacted in a stereotypical way. Most did so in a productive manner with the nascent paraplegics asserting a subjectivity independent of their corporeality, their wheelchair space, at this early stage of their paraplegia. In the main, relationships adjusted appropriately.

'**We have reserved a space for you.**'

When the paraplegic visits friends formally for the first time, the hosts are presented with a real problem: where is s/he to be put? Their living space is designed for walking bodies, bodies which occupy different and less space. The obvious solution is to shift furniture, create a suitable space. This is both a blessing and a curse for the paraplegic: a blessing insofar as the para knows the obvious, wants to be as unobtrusive as possible and a curse in that often that special, reserved space becomes a prison. Once in his/her space the paraplegic is captured by those occupying adjacent space. This might be pleasant or painful for frequently the space is occupied by a bore who just loves a captive audience. The paraplegic just cannot get up and walk away for, even if space is available elsewhere, s/he risks offending the host. Moreover, the paraplegic is sitting at a different level simply
because wheelchairs are higher than lounge chairs. The effect can be quite alienating. In a play upon words, one para observed to me, ‘You’re there, but at a different level.’

This can be even more so at larger gatherings, a party for instance, where people are standing around conversing so that different spatial relations again obtain. To engage in conversation the para must talk up to people who look down on him or her. This is assuming the para has been seen, is not totally overlooked, or is part of a group. If not, joining a group presents a number of problems. A walker can unobtrusively join a group and enter the group-life quite easily when the occasion arises. The para by virtue of his/her geometry must barge his or her way into the group, upsetting the spatial dynamics of the group interaction. Similarly, the paraplegic, in negotiating a path through a crowded room, experiences difficulties of a different order which are in themselves quite alienating: s/he must patiently and continually excuse herself for being as s/he asks people to make way for her.

A good illustration of the effects of social geography was provided by the paraplegic who was a keen yachtsman at the time of his accident. He had sailed competitively for years and was a member of the local yacht club. He explained how his social geography changed, and with it self, when he returned to the club in a chair:

... I found that when I was down there - they use to have evenings ...they would video the boat races. And I just found out that when I was sitting in a wheelchair you just got pushed into the corner....they put it [TV] above your head and you had to look up like this all the time. And you couldn't keep a conversation going...and I thought, 'Well if you're not in it, you might as well be out of it.' Its alright when you are with it....But jokers would stand in front of you ...especially when they had a few beers. (m,44,6)

Because the world now touched this paraplegic-wheelchair-body so differently, because the structure of his space had changed so radically and he no longer fitted the yachting world, he allowed his membership of the yacht club elapse and developed an interest in para sports.

Finally, there is the social geography of the streets. The way in which the changed spatial relationships affect interaction and constitution of self:

...in town, because you are lower than everyone else, they don't tend to see you. I get people walking over the top of me and people tripping over me. And I smack into people. You just can't help it.... (m,21,2)
The frustration associated with assuming the status of obstacle, running into people, apologizing for being, means that some paras avoid public space. Others just accept that their geometry has changed, that they occupy different space and that others will have to walk around them.

SUMMARY AND CONCLUSIONS

In this chapter motor and sensory impairment have been discussed in terms of how these losses alter the boundaries and nature of the paraplegic body and the effect these changes have on subjectivity. The restoration of mobility to the paraplegic body involves the mechanics of a wheelchair which gradually extends the corporeal boundaries: the paraplegic body grows, assumes a different geometry, occupies different physical and social space. The associated technologies (cushions, catheters, uritips/sheaths etc.) act like temporary organ transplants, a melding of body and machinery, further extending the paraplegic body. The altered interoceptivity of the paraplegic body (that is, the loss of tactile sensation and the gain of involuntary muscle spasm) acts in concert with the altered corporeal boundaries to call into question the ontological status of the paraplegic body-subject.

Being anchored differently in space, the paraplegic body-subject perceives the world quite differently: horizons are lower and the 'lived distance' that binds all things to the paraplegic body shrinks, altering the 'scope' of the paraplegic's life considerably (Merleau-Ponty, 1962:286). The world now touches the paraplegic body quite differently, altering profoundly the spatial relationships with objects and people. In turn, the power relationships inherent to social interactions change with the paraplegic mostly having to look up to others while they look down upon him/her. The next chapter examines social relationships in the personal and public space of the paraplegic body-subject.
Chapter VII
THE PARAPLEGIC BODY-SUBJECT IN SOCIETY

The paraplegic body is not just experienced singularly; it is a profoundly social body, which is lived, experienced, interpreted, acquires meaning in a social context in which it is read, judged, evaluated, received, or rejected. More importantly, it is not just a body which is interpreted, given meaning, dismissed, or welcomed, but an embodied self. In this way individuals begin to understand both their bodies and themselves in light of the social meanings and value placed upon their outer, corporeal appearances. In this chapter the effects of the creation and imposition of meaning and value on the bodies of paraplegics in personal and public space are examined to determine the role they play in the way paraplegics constitute themselves as subjects. The ways in which paraplegics are able to deploy their bodies in recreational activities are then scrutinized as part of the subject creating process. The chapter concludes with an examination of the notional 'paraplegic community' in Aotearoa/New Zealand and its role in the creation and maintenance of paraplegic subjectivity.

THE PERSONAL SPACE OF THE PARAPLEGIC BODY-SUBJECT

The process by which paraplegics define and redefine themselves as subjects in relation to their paralysis is very much shaped by the reactions of those who shared their personal space. Most named their immediate family, friends, and family and friends as the most significant people in their lives at the time of their accidents. Metaphorically speaking, these people were the 'oil' in the process of transition from being non-disabled to paraplegic.

PERSONAL SPACE 1: FAMILY

Parents
Given that most of the paras I spoke to were young at the time of their accidents, it was not surprising that most perceived their parents as taking it, their paralysis, very hard at the time. One (m,18,7) prefaced his comments: 'It would have affected the parents more than it actually affected me I'd say.' Another para had to deal with parents who only had stereotypes to draw upon:
Well it was a case of they didn't know how to take me. Like I said before, it was a general image of a paraplegic is a nut case...it took a lot of training to get them ...I was still doing the same things being the same person they wanted me to go and join these bloody clubs and everything disabled clubs and I said 'no bloody way! I am not interested.' ...they have come to accept to let me do my own thing. They have been good .... (m,17,6)

One can imagine the anger, frustration, and despair experienced by that nascent paraplegic when his parents, gropping for meaning, imposed a totally inappropriate subjectivity on him. There is also the suspicion that he too saw himself in these terms: he was raised in the same social milieu, same belief system, as his parents. The flip side, however, is really positive in most cases: it goads the child into proving that s/he is still the same, an OK subject, even if the body has been radically transformed. Take, for example, the farmer's son:

... not taking over the farm affected my father ... being an only son ... I was determined to try and do it. To try and succeed as a farmer. But then he, my father ... and I could see after a while that it just wasn't practical. (m,18,7)

Being a disappointment to both himself and his father did not mean, however, total capitulation. It just meant a change of scenery, a change of self:

It annoyed me ...I didn't ever want to work indoors. I liked the outdoors. That was the hardest thing....I took on a completely different way of life....going into town [meant]...Having to adapt to town with all the people around. Got to take on a different image in town. (m,18,7)

For this subject it was not just a case of becoming, of being a 'paraplegic' it was also a matter of becoming a 'townie'. The story does have a happy ending:

We get on very well now. They [parents] accept me for what I am. They are very pleased to see me with my life and business.

His general demeanour suggested that now he also gets on very well with, is comfortable with, is pleased with his new self. In terms of parental relationship things were not going so well for another para. While she was living her paraplegic-body quite successfully, her father had yet to come to grips with her situation:

... [he is a] total mess....He tried to blame the accident on himself....I'd asked him to check the tyres a few weeks before and he hadn't ....he now thinks I'm not perfect like I used to be ...and he finds that very hard to accept....I can only handle him in very small doses - I can't stand him. We went through a lot of counselling and that with him, but he's got this mental block....that's the
way he is before my accident. My accident just brought it out more....its made me stronger....I think 'what's the hell wrong with you guys? I can still do everything I want to do. I'm quite happy, although things might take a little bit longer.' You know? He'll burst out crying if I make the bed or anything! I think, 'Well shit! Lucky I can make the bed. What would you think if I was a tetraplegic ...just sitting there like a block all day?' (f,21,1.5)

Some background information sheds some light on the above. The parents had worked their way up from 'lower class family' backgrounds and were now firmly ensconced as respectable members of the upper middle class; she was a partner in a successful business. However, the circumstances surrounding the accident are probably more relevant in explaining her father’s reaction than her paraplegia. She was drunk in charge of a motor vehicle, crashed and killed her best friend. She was subsequently charged, convicted, and served a sentence in a woman’s prison. I suspect that this, more than her paralysis, makes her 'not perfect like I used to be' in daddy's eyes. Its the loss of class status rather than ambulation that is more devastating for him; he cries for his daughter the ‘ex-con’ and her damaged reputation rather than his daughter the cripple. She prefers to place the accent on the latter; she can do something about that by being as independent as possible; people will admire her independence but never her conviction. And besides, a paraplegic occupies a higher position within the disability hierarchy than a tetraplegic. In short, the independent paraplegic subject is far more palatable a prospect than the crippled ex-con.

On occasion loyalties were tested, leaving a residue of resentment towards one parent:

The family were pretty good. Apart from my father he can’t really accept that I am in a chair....he is sort of coming around now but at the time of the accident Mum had to face it all on her own whether I was ever going to walk again because Dad wasn't interested in finding out. ...[We were] fairly close at the time but I don’t think I will ever forgive him for not being there ...when Mum needed him.... (m,17,5)

Occasionally, parents reacted in ways which were quite negative: they became martyrs for their children in a variety of ways. Notwithstanding the considerable sacrifice involved on the parents’ part, it was quite clear that strings were attached. First, it was dependency creating, second it was about imposing a particular subjectivity, third it was domesticating, controlling:

... another thing that we were really annoyed about ... she [mother] stopped work to look after me ... she wasn’t exactly in a [financial] position that was very good for her. (f,23,4)
They had to pay for the alterations to the house. It seemed the only option where I could go was back to my parents place...to go home and live at home...you know what mothers are like...poor crippled son...Used to get on my wick a fair bit...I had to get out...away from my parents. (m,18,14)

In reflecting on his parents’ reaction to his accident, the next para captures the essence of what most had to say. His reading, ten years on, of the collusion, the silence between self and parents in the collective accommodation of his paraplegia, is very perceptive:

My mother...just blew her away totally.... My father he wanted to go and kill my cousins [who had taken him out in the car which crashed] ...my grandfather thought I was going to die because I couldn't walk.... I think they’ve [parents] accepted it but they haven't accepted it, you know? ...like I’m going to be in a wheelchair for the rest of my life but I still hate it. So I think that's what they look at as well, you know? My mother she spoils me [like] ...a little kid, or something like that. (m,15,10)

In summary, grieving parents can be an impediment to the rehabilitation, the re-embodiment of self, the re-enseling of body of their newly paralysed child. Interestingly, fathers seemed to present more problems emotionally than mothers. This might be explained by the social convention that fathers provide for and protect their children, especially daughters. Sons are there to inherit and continue the family name/line; paralysis devalues sons in terms of procreation, protecting, and providing.

Most parents, however, are positive forces in their child's re-embodiment. Their initial fears are assuaged as their child grows into, enselves and successfully deploys his/her paraplegic body. Virtually all parents played no small part in this process just by being there, accepting, loving, negotiating with medical professionals, Accident Compensation officials, and so on.

**Brothers and sisters**

Siblings played a crucial role in supporting the enselvement of the paraplegic body. Initial response was important: 'when I had my accident my brother was in Perth and my sister in the States and they both came back to see me whilst I was still in the acute stage. They just dropped everything and came back. And that was really good and I thought "Wow. I must be a really good guy"' (m,20,4). However, sibling acceptance can be double edged:

...[my brothers] still think of me as the same person and I think its good they do....in some ways ...it wouldn't hurt them to know how difficult some things are to do. Because they seem to think I should be out working and I should be doing a lot more. (f,21,1.5)
This theme is continued, albeit slightly differently, by mothers talking about their children's reactions to their paraplegia.

**Children**

Mothers, when talking about their children's reactions to their paralysis, usually began with reference to reactions from the broader family. Mostly they commented on the cohering effect of their paralysis on the family:

My family was good. They all sort of were more closer together than we'd ever been....my boys grew up faster ...'cos they were only young and they grew up very fast....they don't see me as a person in a wheelchair. They still see me as Mum and doing the things I was supposed to do before. (f,44,8)

Another mother commented on the 'disappearing wheelchair' effect, and pondered the implications:

... [Family was] marvellous. No they were great. They were really supportive they were really helpful and they really did what they could to make it easier. But the novelty wore off and now I just get treated like a normal person and they don't sort of make any concessions ...or very few. Sometimes I just don't know if it's a compliment or an insult ...and you feel sometimes that you wish they'd say, show a bit more sympathy ...more consideration. This would make things a bit easier. And then again you think they say we sort of forget you know. We don't think of you as any different. So I suppose, in some ways, that's a compliment. (f,33,11)

It is not surprising that the children make very few allowances for their paralysed mothers. They had never known her to be anything other than a paraplegic mother, a wheelchair mother; why should they make any allowances? The mothers, on the other hand, were saying quite clearly, 'I am different. Living a paraplegic body requires extra energy, extra planning, extra effort.' But again, the mothers face a dilemma: is it complimentary or insulting to be taken as normal? What does it say of me? For the sake of my children and cost to myself, should I collude with their perceptions of me as 'normal'?

**Spouses/partners**

When a spouse or partner gets paralysed the nature of the relationship is irreversibly changed. In effect, the non-paralysed partner has to live in intimate relationship with paralysis. That is not the same as living a paraplegic body, but it is pretty close. For the

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1 See p.249 for a male para who makes similar comments in relation to his workmates.
paraplegic female there is the question of performance in terms of appearances, sexual attractiveness, child rearing, and housekeeping. For the paraplegic male many doubts are introduced about his ability to 'perform' as a male, to provide, to protect, to be a good father. The effects, real or imagined, can be very corrosive:

We were doing alright for a wee while there, but we just sort of had fall outs all the time, eh? I don't perform like I used to so I suppose that is the main factor and after that it just went down hill from there....it was sort of in limbo....she [would] turn her back and walk away sort of thing ...you couldn't ask a straight question and get a decent answer - you had to guess. That was the worst part. (m,32,2)

At the time of the interview, the man's wife was seeking a divorce. He had no doubt that it was his paraplegia which was at the root of the breakup. But, as the interview progressed it emerged that this man had a history of violence prior to his paralysis and that things had not changed since. I suspect that there was more to the story than he had told me, that paraplegia can be a very convenient scapegoat.

Marriage-type relationships are not based entirely on sex. There are other important considerations such as what a couple do together recreationally. Remember, we are talking about mostly young couples, one of which get paralysed. Such couples are most likely to be involved in physically active recreation and paralysis can have a devastating effect on their relationship:

... my wife was 24, when I had my accident and she was reasonably young and she still had a lot of living to do and I had my accident it sort of held her back....We used to go on trips together quite a bit ...tramping or whatever. So 'cos I couldn't do those things any longer it meant that she was limited. I was devastated [when the marriage broke up] because the one thing that a person always dreads is loneliness. And you know you have enough time to yourself to be able to think about things too much....I accepted my paraplegia almost immediately ...but accepting that my marriage had broken up was [much harder]. (m,27,7)

This man had since remarried. Both he and his wife were very happy and spoke positively about the way his paraplegia had forced them to discuss a number of issues prior to getting married that they otherwise might not have. His wife had made the commitment with her eyes fully open to the physical, emotional, and medical implications of paraplegia. This was very affirming for his sense of self worth.
As already mentioned the majority (80%) of people who get paralysed are young males. Such people are just beginning to explore their masculinity, sexuality, relationships with the opposite sex. For young men paralysis is devastating, particularly the loss of feeling and the ability to achieve or maintain an erection at will. It challenges their self perception, their sense of manliness, their future in the relationship and sexual market. These concerns conspire to load the way current girlfriends react to their newly paralysed boyfriends with meaning:

When I had my accident she kept coming up to see me and all that. Every time she did come up and see me I would ask her did she want to carry on the relationship and she would say "Yes. I still love you and want to carry on the relationship"....it puts a completely different outlook on life once you know she still loves you. 'Cos I know when I was in the spinal unit other guy had just started breaking up with his girl friend and he reacted somewhat wickedly, eh. (m,20,2)

This section has focused on the exceptions rather than the relationships in which paraplegia was successfully accommodated because the former give insight into the latter. Most marriages and partnerships do survive paralysis and remain intact. Moreover, the paraplegics stressed that the support, acceptance, and love they received from their partners/families was a very positive force in their coming to terms with themselves and their paraplegia, in enseling their paraplegic bodies.

However, before moving on to the next section, a cautionary tale about the pitfalls of marriage. One para had recently married a nurse he had met when in hospital for pressure area care. A common reaction to his marriage has since been:

So everybody, people that don't know me say to my wife, "oh gosh it must be really hard living with him"....They're [assumed] martyrs who haven't married you because they love you but because they are sorry for you, or want to nurse you or something. (m,21,6)

Such reactions draw upon stereotypes of both disabled males and a woman's role as wife. Being in a wheelchair the man must be helpless, unable to provide material support, and be a lousy lover. She must be making a great sacrifice, to give up so much. Once a 'wife' it is

\[2\] Unless otherwise stated all sexual relationships can assumed to be heterosexual. Only one para defined herself as homosexual.

\[3\] Ninety percent (90%) of the couples who were living together at the time of the accident were still together at the time of the research.
the woman's duty to keep house, be a good homemaker, and care for her man, especially if he is an invalid. Such stereotypes persist even if both partners work and live interdependently, have a non-gendered division of labour about the house, and seem to enjoy each other's company (all applied in this instance). Of course it is a lot easier for a paraplegic (anyone for that matter) to live in relationship than on his/her own. Mutual emotional and physical support is likely to see a division of labour emerge that is based on physical ability rather than gender. For example, it is logical for the non-paralysed partner to mow the lawns and to change light bulbs while the paraplegic might do a greater share of the cooking, cleaning, and ironing.

PERSONAL SPACE 2: FRIENDS

Besides family, friends are the next most significant group of people in the process of the enselvment of the paraplegic body. And while it is reasonable to argue that work colleagues constitute important others with whom one shares one's personal space, the nature of the relationship only occasionally measures up to that of close personal friend. For this reason workmates/co-workers/colleagues will be discussed in the section on the labour market in the next chapter.

Friends
The sting in the tail of the old adage that we can't chose our relations but we do chose our friends is that our friends choose us. People are more likely to relax with their friends, go out shopping, go to the cinema, visit the museum, play sport with, go to the pub, and party with friends than with their relatives. Friends choose to be with us so we feel we can trust them to confide in. We are seldom lonely when with friends. Friends validate us: they say 'you're OK.' Thus, the way friends responded at the time of paralysis was pivotal to self-perception, to growing into, dealing with the paraplegic body: 'My mates were just unreal some of them ... would come to the hospital.... They were just great. They just got me going and without them it would have been horrible' (m,19,12).

When visited by friends a process of negotiation begins. Friends can be expected to be ignorant about the implications paraplegia has for the life world of their paralysed friend and their friendship. The onus is on the paraplegic to convince friends that s/he is still the same
person, the same self with whom they were so friendly, that they must not be afraid, ashamed, or jump to any conclusions:

I noticed some of them were a bit cautious about what they said. Others would be really direct and I didn't mind that and others said, "Well do you mind talking about...?" and I said, "No I don't mind. Ask away"...[They were] really supportive. At the time I didn't have a car they would come around and say lets go to the pub etc. (m,20,4)

... they [friends] were fantastic. Very upset ...you really know that you're still the same but often they don't really know this. But they were fantastic. I found out how many friends I had. So much support and love and, you know, it was brilliant, yes. (f,26,10)

It is obvious from the above that steadfast friendships are a great boon to maintaining a positive sense of self during the course of learning to live the paraplegic body. Both of the paras quoted alluded to the phenomenon of second guessing of what it would be like to be paralysed, of how I would cope? While straight answers can be given to friends, strangers do not often put the question. Second guessing bedevils paras as they try to make their way in the wider community, especially when looking for work (see below).

Others spoke with a mixture of bemusement and bitterness of the friends who abandoned them:

A lot of them were quite shocked and took it even harder than I did. To think that I would end up in a wheelchair... A lot of mates, that I thought were mates, I no longer consider as friends. There was one guy that said he could never face me because I was in a chair. He'd always want to remember me as the guy that was able to walk around. (m,27,7)

One particularly, I used to flat with, she's really good on the phone and writing letters. When it comes to seeing me, she can't handle it too well at all... (f,21,1.5)

A number of reasons can be advanced for the irrational behaviour of the friends noted above. However, I think that the most explanatory power can be gained from the work of Merleau-Ponty (1962) and Shilder (1935) on the body image and intersubjectivity which was discussed above (pp.22-24). To recapitulate, the body-image is socially and mutually created in the presence of others. It, thus, comes as a bit of a shock to be confronted by a body which, while living, is irrevocably changed and strange. Most can accommodate this change and friendships endure. However, for some the paralysed body confronts them as an enigma,
as a thing that elicits fear, dread, embarrassment. It is folded in on itself by virtue of its lack of function and prospects for action; like a vortex it sucks in life and movement rather than offering the possibility of mutual corporeal expansion. The respective corporeal schemas can no longer embrace meaningfully and the possibility for intersubjectivity ceases. The two previous quotes lend weight to this argument. The sight of his friend in a chair so distressed one person that he chose not to see him again; the second, is far more composed during long distance communication than at face-to-face interaction.

Some paras found that given time some mates did come round to renewing the friendship. But the damage had been done:

I lost a few mates ...because they couldn't accept the chair ...but I have found out a lot of them have actually come back to talk to me now that they...realise that I can do similar things to them....It hurt ....I still treat them as mates, but not as a trustworthy sort of mate. (m,17,5)

The following captures the variety of reactions from friends:

Some of them were OK. Others just walked away. A lot of people that I didn't know that well were brilliant. A lot of people I knew real well, but didn't have much to do with, were bloody brilliant and people I knew real well and were real close to were - they just walked away....That's the way that it goes. I was compensated for by other people. You find out who means a lot to you and who doesn't. (m,17,6)

Acceptance, approval - call it what you like - from significant others is not only crucial immediately following the accident but a vital factor in the ongoing process of rehabilitation and self-acceptance. One paraplegic neatly encapsulated the complex inter-relationship between social-approval, level of support, and self-acceptance:

... for a start I got thousands of letters and lots of visitors and lots of presents and lots of, you know, reassurance and that. I think it ...is the same as when someone has died. They will decide ...how long it takes for someone to get over something ...give them that long ...be supportive and then they would expect you to have gotten over it by then, and then things would be back to how they were. Or maybe they would think "she should have been driving her car a few months before"....things don't always turn out the way that they should be and ...you lose a significant amount of the support that was there right at the beginning ...when you don't really need it [all]....probably about now, in the last year or so, I could have done with more then, than maybe at the beginning. Until you do that first situp in a wheelchair - you know it is great while you are lying down everyone can come in and just joke and treat you just the same - but it is not until you get up and sit in this chair that you really... (f,23,4)
Life goes on. Friends only have so much time to give. They get married, have families, and do all the things the paralysed person once hoped to do. A true indication of the social meaning of paraplegia cannot be gained from within the protective environment of the Spinal Unit or that of private, family space. Social rehabilitation begins upon discharge; it is in public space, the wider community that our 'social selves' are formed.

THE PARAPLEGIC BODY-SUBJECT IN PUBLIC SPACE

Most of the paras I spoke to complained that in the Spinal Unit they had been given a view of society through 'rose-tinted' spectacles. They expected it to be totally accessible, and the people welcoming and accepting. This view was generated by the physical environment (purpose built Spinal Unit, a shopping mall built to Code 4121⁴), by the attitudes of the non-paralysed staff to whom wheelchairs were quite normal, and by the partial nature of the programme which focused almost entirely on the corporeal rehabilitation.

The idealized society

One young man got quite a shock when he moved back to his provincial home town. Here he found the kerbs too high for him to jump up and the shoppers quite inconsiderate:

... they didn't train you up enough to know what the outside world is like. They used to take you out in the Spinal Unit vans ...to places that were made for paras. And when you are out in the real world you don't go to places that are made for paras....they said was everyone's going to be nice to you type thing....People aren't nice ...they give you a picture version from a story book how society is - and it isn't .... (m,20,2)

Another stressed the inhospitable social environment he had to confront when he returned to his parent's farm:

... a completely different environment. A different sort of people to contend with, to cope with. I found it very different ....My social life virtually came to a halt until my mate came around one night and just picked me up and dragged me out and I had no opportunity but to go. And that is when I actually got going again. I don't think that I can really accept the people around this area. (m,17,5)

⁴ Mandatory building code to ensure all new buildings are wheelchair accessible.
Friends can be indispensable when the paraplegic body first ventures out onto the streets: ‘I didn’t like to go out to start with....If I had someone walking along beside me that I knew, it never used to worry me’ (m,18,7). Why should going out into the public domain be such an ordeal for the nascent paraplegic? One para, echoing the views of others, placed the blame squarely on the Spinal Unit, which he believed masked the alienating effects of public space on new paras. Instead, the Spinal Unit should:

... make people get out by themselves while they are still in the Spinal Unit....Instead of going out together in a whole group and in a bloody van and all pushing around the shops together ...you are still in your little group....When they get into the community it is totally different - Christ, what a shock! (m,30,8)

What then, is so shock-inducing about the wider community to the paraplegic body-subject? A cluster of discrete, sometimes interrelating, factors were nominated during the course of the interviews: self-consciousness, the public gaze, infantilization and patronage, the loss of anonymity, becoming public property, being the object of different treatment.

**Self-consciousness**

All the paras I spoke to recalled how self-conscious they felt when they first ventured out in public in their wheelchairs. With time the intensity of these feelings diminished and it became quite ‘normal’ to attend to daily business in a wheelchair. A number of the reasons for self-consciousness were captured nicely by a woman para as she talked about the first time she went out from the Spinal Unit:

... I can remember when I first went out everybody looked at me, you know? I had a blimin’ catheter in and this bag pinned on to my skirt and I was dreading that that was going to fall out. And I had to be lifted in and out of the taxi because I couldn’t transfer yet. ...I had to sit in the aisle at the show....I felt so incredibly self-conscious. (f,26,10)

Its very much a case of this paraplegic body-subject knowing which parts of the body work and which do not; of the catheter in the body, the urine bag attached to the body and hidden beneath her clothes; of the potential for embarrassment if technology failed, the public humiliation, the fragility of the situation. Of course, the vast majority of the theatre patrons were probably not even aware of her presence, let alone the details of her plumbing system. But she was. And that is what counts. However, self-consciousness recedes as the subject grows into, becomes comfortably and organically body-subject. The previous woman continued:
... It’s taken me - I don’t know how many years - as the years have gone on it’s got less. And now I don’t even think about it. I know people look at me. People that are with me notice it, but I don’t really notice it any more.

(f,26,10)

It is simply a case of making the abnormal normal. After a while it comes as quite a shock to learn from companions that people, shop assistants are looking, reacting, treating you differently. In a strange inversion of being, one’s friends become self-conscious for you (and frequently outraged!). Not surprising really, it is the paraplegic body-subject who has made the abnormal normal, not the upright, ambulant, ‘normal’ body-subject.

The hidden, worrying, existential experience of the paraplegic body is only partly responsible for self-consciousness. The shocking factor of ‘staring’ compounds uneasiness.

The public gaze

Without exception, all the paras I spoke to commented on the dis-ease created by strangers staring at them. Staring was perceived variously as rude, ignorant, intrusive, abusive. The majority of paras grow immune to the ‘stares’ after a while and may even challenge the offender; for others, the gaze is a constant reminder of their difference: ‘one thing I can’t really handle ... is the [stares] you get when going down town...I hate people looking at me ...’he’s different from us’ type of thing’ (m,20,2). A few in this category avoided the public domain at all costs and remain within the safe environs of home. At the other end of the spectrum plans are made to go on the attack:

I don’t like being stared at. To me, staring is rude ... and that’s just the start. You get people scratching their head "is this guy for real or what?" They say time takes care of that, but I’m waiting for time ... I think once my dog’s two years old and brainy enough [and] I don’t need a leash on him and I just "Bang!" [clicks finger] He’s alongside and I’ll go anywhere man. Anyone want to fuck me, you fuck him first!

But you can’t set your dog on someone because they stare at you... Aw, it intimidates me in a way that hassles me. I think I would, eh. I won’t even hesitate ....I don’t want to explain myself to nobody. Can you understand that? If its wrong not to explain yourself to anybody maties, I’m going to be wrong for the rest of my life. I don’t mind kids - that’s understandable - but when you get someone who is 45 years old and you see them acting just like those little kids act. NO, NO that’s not me, eh? (m,29,1)

Admittedly, this is a young para talking and there might well be a bit of bravado, overcompensation, in his plans to meet the challenging behaviour of the non-disabled community
head on where power is at the heart of the matter. Or, more accurately, the loss of power and the development of strategies to enable the deployment of physical power from a position of weakness. The man in question had strong feelings of physical vulnerability coupled with a deep sense of negation and inferiority because of the loss of his ‘manhood’. Prior to his accident he had spent a lot of time in the bush on his own hunting with his dogs. When not in the bush, he was, by his own accounts, somewhat of a philanderer. Now he could not walk nor get an erection, he had lost his independence, his bush, and his manhood. His sense of self was thoroughly abased; people staring at him reaffirmed that abasement, magnified his sense of powerlessness. Unleashing his dog on the culprit, a kind of pseudo ejaculation, would not only punish but also go some way to restoring the power imbalance. Indeed, it would reverse that imbalance. Moreover, his relationship with his dog was one which paralysis had not changed, which established a hierarchy in which he was master. Overriding all these concerns was the fact that this person used a lot of marijuana to ease his root pain. His heightened (distorted?) perceptions probably make an already fraught situation even more fraught, hair-triggered.

However, most of the paras I spoke to eventually adopted an equally confrontational, albeit less physical, response to strangers who insist on staring. The most satisfying strategy seems to be a brazen approach, disability pride at its best:

... it used to worry me...now I just stare back and they look away first. It is never me!...I just say smart things or, you know, if someone ignores I just tell them straight out; tell them that I think they are being rude. (f,23,4)

Which leads nicely into the next factor which many paras find more shocking and offensive than being stared at. And that is being ignored, talked over or about, or being singled out for special attention.

**Infantilization and patronage**

All paras continue to experience the ‘not being talked to’ syndrome. It generally occurred when they were out shopping, socializing, or working with non-paralysed body-subjects. A young man recalled when:

... [a] waitress comes up and goes "would you like to order ...." And the three able-bodied gave theirs and then she turned to the able-bodied people and goes, "Oh. What would they like?" ...I've gone into a shop and I've had an able bodied person behind me who's a friend ...and the people behind the
counter look straight ahead and talk to the person behind me. And you go, "Excuse me. Over here. I'm the person that's buying." (m,20,2)

This is total negation of the adult. It is treating the paraplegic like a child who is incapable of independent thought. An older man talked about the humiliation he experienced from a sub-contractor he had contracted to assist with a project:

They seem to think that if you are sitting in a wheelchair its like you are sitting in a high chair....I am talking about on the job too. Just because I am sitting in a wheelchair they think you have a low IQ. In a lot of cases I have got more experience than what they have got because they have just come out of their time....I would like to have a go at them and say "Who the hell are you? ...you are telling me what I want, not me telling you what I want". (m,44,6)

There is a point where infantilization slides into patronage of the worst kind. Take the following for example. A mother in her late forties is out shopping with her son:

... they usually ...look at the person over my head and ask if they can help....sometimes they say to me "go and ask your husband see what one your husband will choose". And I look at her and [say]..."that's not my husband, that's my son"....They must think I'm cradle snatching or something because he doesn't look like my husband at all....they can see he's got a baby face....he's only about 18 at that time. (f,44,8)

Coping with the ongoing scrutiny, the patronizing attitudes, as well as resisting and rejecting the imposition of a particular subjectivity based upon body appearance and stereotype, gets tiring. Easter and Christmas are especially dangerous times for being publicly singled out from other adults: 'I am sick of being offered lollies by Father Christmas every bloody Christmas ...who hands out MacIntoshes like to the IHC people ....' (f,23,4).

The paraplegic body is highly visible out on the streets because it occupies a different space and uses a different means of mobility, the wheelchair. For a whole variety of reasons, some within the general public assume that this turns the paraplegic body-subject into public property and grants them the licence to intrude, to ask all sorts of personal questions, to lend a helping hand.
The loss of anonymity: becoming public property

As mentioned elsewhere, one of the most shocking features about the wider community is the way people insist on lending a helping hand. Curiously, many of these helpers seem to develop a hearing impairment when told politely that their help is not needed:

... the worst one is older people ... trying to help you and you say "No I'm OK" but they still grab the wheelchair and start putting it in the car and you can hear the paint go "scratch, scratch". They make it harder for you. They just don't seem to understand that you can cope. (m,21,6)

Another captured the effect public scrutiny and unsolicited help can have on subjectivity:

They all keep an eye on you making sure that you are all right and don't really allow you to do your own thing. Always there jumping in and "Oh can I get that off the shelf for you?" when you are quite capable of getting it yourself....[makes me feel] Stink...like I'm not capable to them. (m,17,5)

Paraplegics are caught in a double bind when these situations arise. On the one hand they can refuse unsolicited help and get abusive if the person insists on helping. On the other, they can not get abusive when the person insists on helping and in the process makes the procedure more difficult or creates a public spectacle. The paraplegic has things other than his/herself to consider. While extremely mobile and fully capable, s/he represents all disabled people many of whom are in far greater need of assistance than s/he. If this 'un-helper' is abused away, it might never again offer help to another disabled person. In this situation most paraplegics become skilled public relations officers, placing others before self:

If I wanted anything I could always ask. But people don't really know that. They just like to ask ... I don't like hurting people's feelings. It is better to let them have their own way than start a big argument or abuse them because they are only trying to help. But if they insist, then usually you say "No. No its alright" and I do it as fast as I can so that they can see that I can do it. (m,20,4)

Often its a case of the 'tragic and pitiable victim' helping the able-bodied:

... one out of about a hundred occasions ... I'd tell somebody to piss-off....we have needs but so do they. And those people, if they feel they've done a good deed, and they feel better about themselves, so it's sort of reverse psychology in that I've helped somebody else to help themselves. (m,27,7)

After a while most paras lose their self-consciousness in public and get to see the positive side of people. Indeed, a number mentioned to me that a lot of strangers went out of their
way to be civil to them precisely because they were in a wheelchair and, therefore, non-threatening in a violent sense. While such interaction allows paras more opportunity to experience the good side of human nature, there is always that niggle, that double-bind that traps one into accepting unwanted help, or leaves one feeling guilty for refusing:

... people can be very considerate. I didn't realise how people can go out of their way to offer their services....I like to feel that I'm trying to be independent and not wanting to turn to someone at this stage. But I feel am I doing right in turning a person down. Should I consider their feelings? (f,49,5)

The feeling that as a paraplegic one is expected to be more open to public scrutiny, to become a wheeling resource for the ignorant questions of strangers, to be less anonymous is captured nicely in this woman's reflection. She begins by acknowledging her role as educator, a role she seems to welcome, but ends on a wistful note: '...[they] feel as though they can ask us questions....I'm...too willing to answer....It came in with the chair and everyone knows you. Your life is not as private. You just can't go in a shop and pick up a loaf of bread' (f,35,1.5).

**Objectification**

It does not really matter whether it is the public gaze, infantilization, or unsolicited help because all heighten self-consciousness and feelings of objectification. Strangers are most likely to turn the paraplegic body into an object of scrutiny and pity:

Well people that don't know me do treat me differently....They fuss around me in shops. They wonder whose kids I've got when I'm out. Who would let a cripple look after their children? Yes they do fuss around you a bit. (f,26,10)

As strangers become friends the paraplegic body becomes just another person, albeit with special requirements. The previous woman continues:

... people that you know, when you first meet them they see the chair, and now [they] don't even think about my chair. They just see me and they don't treat me any differently. They are as concerned about me going anywhere - that it is accessible and all that sort of thing ....

The above begs the question: if friends do not treat you any differently why do they worry about accessibility? Of course, the paraplegic body-subject is treated differently from the non-paraplegic body-subject. It is just that they get used to been treated as paraplegic body-subjects as they grow into and enselve their paraplegic bodies. They soon notice it if friends
and colleagues do not treat them differently (see above p.249). Paraplegics, after all, make the abnormal normal. Indeed, as time passes it all becomes a bit 'ho-hum' and even the abnormal becomes normal for the normal:

... I am the only paraplegic in [rural centre]. They had never seen another before, so it was a novelty for a while. But now-a-days it is just one of the boys sort of thing and it has been that way since about four months after the accident. Everyone has just been "Oh that's Gerry". (m,17,6)

In larger centres it is an impossibility for strangers to get to know one as being differently normal. A woman recounted the extremes of treatment that she been subjected to since becoming paralysed. In doing so, she appealed for the public to recognize the real limitations her paraplegic body imposes on her mobility and for a discreet and appropriate response. In validating the subject it is a matter of striking the right balance. Her experiences and comments were fairly representative:

You find extremes really. You find people ...either don't really know what to do with you [and] talk over your head like you're brain damaged. Or fall all over themselves to be helpful. Like you deserve special treatment because you know, you're obviously in a wheelchair so you deserve sympathy etc. Sort of go from one extreme to the other you know. Not left alone exactly but just treat[ed] ...like a normal person because you are still a normal person. You're just sitting down.... (f,33,11)

Well, if 'they' are not going to treat you as a normal person one might as well make the most of it.

Wheeling and dealing
Compensations do accrue to the 'wheelchair bound' paraplegic body-subject. Its just a question of identifying them and seizing the chance. The last word should be left to one street-smart para who beguiles, charms, never misses an opportunity:

You are always treated differently. I mean if you put a smile on your face and you come running towards someone looking as confident as anything then people are just blown away, like just seeing people in wheelchairs wheeling around going shopping, walking your dog...so people just treat you differently, you know, like you can go in and bargain. I'll go into shops now and ask for discounts and I know I'll get it because I'm in a wheelchair....they're a bunch of turkeys ...I use what I've got because now and again it can be a real drag and you're hassled in pubs. Pissed people come up to you and put their arms around you and want to kiss you....people dribble over you and buy you drinks when you don't want to. And you're sitting with friends having a quiet drink

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and people come and hassle you because you are in a wheelchair. Tell you how fucking marvellous you are and I always get really shitty and tell them what a bunch of useless, insecure bastards they are and they should go away. You are treated differently, full stop. It’s like you can’t not be. You’re different. If you’re different - you’re treated differently. (m,19,12)

There is a curious (and heartening) sort of logic to the above. A happily enselved paraplegic body-subject. It is a good note on which to finish this section.

LEISURE AND RECREATION

What people do to relax, take time out to be, has an important bearing on the type of person one constitutes self to be. Indeed, many would argue that the real subject is to be found at play reflecting the Marxian notion that consciousness is the product of corporeal interaction with the material world. During the course of the interviews subjects were asked if their patterns of leisure, recreation, and social life had changed with paraplegia. If patterns had changed it was germane to find out how and why they had changed and the effects, if any, these changes had on the process whereby meaning and self-perception is constituted for paraplegics.

Prior to their accidents a clear majority of respondents preferred to spend their leisure time in group activities such as sports. About a third had liked to reserve some time for themselves and spend the rest with friends or family in both active and passive pastimes5 (Table 3.0:290).

Patterns of change in leisure activities

Following their accidents, a majority of paraplegics changed from an active to largely passive mode of leisure activity: "I just can’t do it now. I am a spectator. I watch it on TV but I can’t be bother going to watch it in a wheelchair" (f,23,3). For about a third of the paras, little had changed apart from mobility. These paras were engaged in both passive and active pastimes within the limitations imposed by paraplegia6.

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5 Active pastimes included playing (mostly team) sports, family outings and tramping. Passive included watching television and sports, reading, playing and listening to music, chess and board games.

6 Technology has enabled some paras to continue doing the same thing, only differently. For example, a number now hunt from four-wheeled farm bikes rather than on foot.
A sizable number were, however, no longer motivated to do much, if anything, with their leisure time. A tendency towards reclusiveness was noted in about a third of these paras. The following quote capture the tone of this group:

... many [pastimes] have gone completely. I haven’t taken up anything new. I still play my guitar....But now I can’t run, play soccer, go to the beach, take girls out. (m,17,5)

The medical/health effects of paraplegia imposed severe limitations on what some paras were able to do in terms of leisure and social activities. These effects included pain, the need for extra rest in free time in order to continue working, and the debilitative effects of chronic UTI.

Changes to leisure activities were also gendered with a higher proportion of males having to make changes than females. This reflects the fact that most males were involved in active team sports while females tended towards solitary, passive pastimes before paralysis.

It would be misleading to attribute all changes in leisure and social activities to paraplegia. In a number of cases stage of life cycle was a contributing factor. Some paras said they were just about ready to retire from playing sport and that paralysis had only hastened the process by a season or two. For others, marriage and a mortgage had imposed greater changes on leisure activities then had paraplegia.

**Changed leisure activities: implications for self-perception**

Just over a third of the paras who had made changes in their leisure activities as a direct result of their paraplegia, believed that their self-perception had subsequently changed (Table 3.2.290). Although only a small group is affected, the why and the how of these changes gives insight into the social process whereby self-perception is reconstructed by some paraplegics.

Of the paraplegics I spoke to a significantly higher proportion of females than males indicated that changes in self-perception had resulted from changed leisure activities. A look at the gender differences suggests reasons as to why changes in what paraplegics do in their leisure time modifies self-perception.

Male paras are far more active physically in their leisure time than female paras. This probably has as much to do with having male friends who are prepared to ‘lug’ them around
inaccessible parts of the wilderness and the socially ascribed mores of ‘correct’ gender behaviour, as to do with personal, physical strength. Whatever the reason, by maintaining their links with their ‘able’ pastimes, albeit in a modified form, male paras seem better able to integrate ‘self’, hence their self-perception is less likely to change. Initially, that is:

…it hurt most when I couldn’t go rock climbing, when I couldn’t go fucking diving….But I used to get so much support from people, my friends, close friends they used to take me rock climbing and carry me up the side of cliffs and do all sort of manic things …

Eventually the body does win out:

…that …became impractical as I got bigger and fatter. And also, people’s enthusiasm soon wanes….now …I’m into concrete and lino and tar-seal. (m,19,12)

In terms of how self-perception had changed, the main point to emerge was that the majority of paras now see themselves as losers when it comes to leisure and social activities. This grows out of a deep seated sense of loss and feelings of frustration over not being able to do the things they used to. They may well enjoy other activities but some of the gloss is gone; their choices have been narrowed and they must now be satisfied with second best. The general tenor is captured in this para’s summation of his feelings:

… my active nature has been quashed and I can’t do anything to change that. And all the bullshit about being able to do different types of sports eg para sport doesn’t make up for anything. (m,23,7)

Others saw themselves quite negatively as social isolates. While these paras also saw themselves as ‘losers’, it was in a broader, more painful sense than the first. They no longer saw so much of their friends or attended few, if any, social functions; they had become reclusive yet still longed for more social contact.

For those who long for more social contact there is always para-sports and the paraplegic community where they can mix and socialize with their own kind, isn’t there?

THE PARAPLEGIC COMMUNITY: REAL OR IMAGINED?

Paraplegics are generally portrayed in the media as people who, having lost the ability to walk, devote the rest of their lives to performing extraordinary physical feats in their
wheelchairs. If paras are not returning from international games bedecked in winner's medals, they are busy rowing their way across some piece of water or dragging themselves up to the summit of some mountain. Society may well be forgiven for assuming that paraplegics form a close knit community dedicated to sport and other acts of physical endurance. To see if this assumption had any basis in reality, I asked paraplegics how much of their spare time they spent with other paras and/or other disabled people, and if they were, or had been, involved in para sports.

A sporting community?
I was surprised by how few had been involved in paraplegic sport - a little over a quarter. This is surprisingly low given the emphasis placed on sport in the New Zealand Paraplegic and Physically Disabled Association (NZPPDA) newsletter and other publications. A greater emphasis seems to have been put on sport as an important part of the rehabilitation programme in the early days of the Spinal Unit. This could have reflected the demographics of the population as much as the prevailing philosophy in the Unit at that time. As one para recalled, the patients were mostly young at the time and the physiotherapist keen on sport. For himself personally, sport was something he could profitably put his energy into:

I was always sports minded before my accident so I ...bought a javelin, discus, shot put ...and I just trained ...everyday and I went to...the Games....I got second and third and I was really rapt. And I still kept on training and ...I found I was getting better and better. So that's where I focused all my energy into. Sport, eh? You know, sort of like ...don't let being in a wheelchair sort of fuck me up and hold me back. (m,15,10)

The above captures the sentiments of those who got into sport in a big way. These people were most likely to have joined clubs have joined regional divisions of the NZPPDA which encourages and promotes sporting and social occasions for paraplegics at local, regional and national levels. Many close friendships had evolved amongst competitors across these levels.

For most, however, sport is a transitory phase in which they gain the confidence to function and to be seen in public. Equally important, new paras are introduced to their peers and the informal networks of information which follow:

... the thing is with paraplegics we all have a like injury ...and we all have like problems....The thing is you've got to know where to ask. In a lot of instances you know they [new paras] just don't know where these services are. They soon find [by] word of mouth .... (m,19,12)
As their rehabilitation progressed, less and less time was spent in activities involving other paras until they reached a point where they spent little, if any, time with other paras:

Lots of things that you can talk to people about that you can only talk to disabled people about, you know. Talk about bladders and bowels. Obviously the main topic of conversation. It was really good. Like I don't spend a lot of my life with disabled people but the parts that I do I find valuable. (f,26,10)

The points of departure varied from individual to individual and were dependent upon factors such as geography, new leisure interests, marriage, new social networks, financial commitments, and the like.

A community of interest?

Having noted the transitory aspects of the 'sporting' community of paras, it is useful to take cognizance of those paras who do return to their 'community' via its sporting/recreation dimension. After initially eschewing any sporting or social contact with other paraplegics or disabled people generally, for the paras in question it suddenly seemed not at all onerous to cultivate such contact. A number of reasons can be advanced for this reversal: the not being characterized as 'one of them' syndrome and the avoidance of stigma, the false pursuit of independence, a belief in the unchanging subject, the false perception of having nothing in common with other disabled people and/or paraplegics except a disability. But after a while, many see and realize that they do have quite a lot in common with other paras and that, maybe, it would not hurt to get together with other paras. One such para is quoted at length:

In the first few years of my accident, especially the first two, I rebelled against anything that had anything to do with anything disabled. I wouldn't be involved in disabled groups. I wasn't involved with sports. I always thought that they were really a bit institutionalized and run by people who just wanted to dominate cripples. And I was viciously independent so, therefore, didn't need to talk to cripples at all or have anything to do with them. They were all fucking wankers. They knew nothing and I had all my shit together, you know. But as I went along and matured I knew...that we all can share something and it was really good talking to other people in wheelchairs. Sort of like a club...if you're an accountant you hang around with a few other ones ...and that way you get a lot of good feedback. And I did start playing wheelchair basketball and I really did enjoy it and I became obsessed with it and still am. Something that I really like and I think it's important for people in wheelchairs to have that...be able to participate with other people that are disabled in wheelchairs. Sort of like a club. The guys get together and we, you know, discuss uritip sizes, you know, shitting and pooing and that. You get off that but now and again everyone get pissed and it comes up and everyone tells, says what they think and everyone's got their own idea. No. I think it's quite good being in a club or having something to do with something disabled in some way. (m,19,8)
It is the shared corporeality which over time generates similar social experiences which, in these cases, provides the basis for a shared 'paraplegic subjectivity' and sociability. In essence, as subjects enselve their paraplegic-bodies a convergence of subjectivity occurs which could not be there at the beginning. This, the shared subjectivity, became abundantly clear to me as the interviews progressed. People who were complete strangers to me became confidants as we spoke about their/our paraplegia. Their responses were peppered with 'you knows' and 'ehs' and these were not questions: they were statements of fact, shared fact. The understanding was quite clear: as a paraplegic I did know how 'it' was and that was sufficient. We lived paraplegic bodies. We shared the social experience of paraplegia. We were paraplegic body-subjects. As such, certain standards and codes of behaviour are expected of all paraplegics by other paraplegics. The 'successful' paraplegic is the ideal type against which self and others are measured in the moral community of paraplegics.

A moral community?
Expectations, spoken and unspoken, are first inculcated, picked up, absorbed in the Spinal Unit:

I think it's probably mostly self imposed but I think the pressure is on a para. You know they get you rehabilitated and you’re someone special....You can do it all ....they always, the cross reference to tetra and para is used heaps. That if you're not a successful para, you don't work ...you haven't got a wife or a girl friend....You're not really a successful para and you've really failed in your rehabilitation. (m,19,8)

Later, standards are reinforced at various meetings when transgressors are judged, held up as examples of what not to be, shunned, sanctioned by gossip: 'He's a different type of guy who doesn't work. He gets up at mid-day, watches the soaps and goes to the pub, gets drunk, and comes home' (m,18,7). It is not just a matter of been employed productively, its more a question of attitude, pride, self-care, making the most of what one has:

I haven't seen him for a long time but his attitude towards life is real stink....you just about had to dunk him in the bath with disinfectant he was so ...he had everything going for him his parents are good and everything else. He had no worries about money or anything but he had the attitude to life that it owed him something. (m,30,8)

7 This was an illustration of what Heshusius (1944:15-22) identified as the participatory mode of consciousness. This involves an 'identification or merging' (p.16), a 'bodily knowing ....a nondescribable, nonaccountable form of knowing that is crucial and vital....to understand[ing] both other and self' (p.17).
Some of the older, ‘successful’ paras were harsh in their criticism of the younger paras who, in struggling to come to terms with their paralysed bodies, inflict retribution on those dearest and nearest to them. Or, who used their paraplegia as an excuse to be self-centred, self-pitying, or for character flaws that were present prior to their paralysis. An older para is quoted at length on these issues. She begins by discussing the trouble some friends had had with their son immediately following his discharge from the Spinal Unit (they had asked her for advice). She uses this as the starting point for a longer dissertation on coping with paraplegia, especially those who attribute character flaws to their paralysed bodies:

... Family had a dreadful time. Gave them a heck of a hard time. He played on every emotion he could possibly do. He can’t blame anyone else for his pressure areas. That would be the sort of thing he would do. He’d yell at his mother at two o’clock in the morning to empty his leg-bag. And he’s a para!...he would just not look after himself at all. ...I still feel that the person that you are inside before you have your accident either makes or breaks you....you see some people that just get on and go out. They grab life and they live it. Because that is what they were like before. You get someone that sits around feeling sorry for themself and “I can’t work, I can’t do that”....The accident comes, every one has tragedy and crisis in their lives and it’s how they cope with it after is the sort of person that they are. So much is made of "well you know that he’s got a broken back now". I believe a tetraplegic must be dreadful because you have so much more of everything done for you. ...Some people like to use paraplegia as a bloody great excuse.

Throughout this quote the moral evaluation of a paraplegic in particular\(^8\) and paraplegics in general is evident. Paraplegics must be physically independent; they must get on with life and not sit around feeling sorry for themselves; they are incredibly lucky/fortunate in comparison to tetraplegics; they owe it to themselves and their community - the moral community of paraplegics - to be ‘successful’. If not, they were ‘no-hopers’ before their accidents and will always be ‘no-hopers’. Their lack of success has nothing to do with their paraplegia and everything to do with ‘my’ status as a paraplegic: it legitimates the ‘tragic’ and ‘dependent’ components of the disability stereotype. And mud sticks to all paraplegics of which I am one.

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\(^8\) This account contrasts with that given by the paraplegic in question on p.169. From his description, it seems quite clear that the lack of proper toilet facilities were to blame for his pressure sores, not character as proposed by the paraplegic just quoted.
A stereotyped and stereotyping community?

While it might ultimately be true that any 'moral' community of paraplegics has its basis in stereotype, there are two other aspects of stereotype which need to be addressed. First, paraplegics in relation to the broader negative stereotyping of disability and disabled people in general. Second, the stereotypes paraplegics have of other paraplegics.

Broader disability community

On becoming paralysed, the body-subject is made a member of the broader disability community. No one does this voluntarily because immediately body and self attract the negative meanings and values that have accreted to disabled bodies over time (see Chapters III and IV). As formally non-disabled people, traumatic paraplegics know the contradictory mixture of pity, horror, admiration, and disgust with which disabled people are held by the (non-disabled) community. In seeking to avoid this stereotyping many paras refuse to have anything to do with other disabled people, 'just because I'm in a wheelchair, doesn't mean that I have to mix with disabled people' was the refrain I heard often.

Having a disability does not necessarily make for commonality of interest nor for the best grounds on which to base a friendship. While not dismissing the idea of making such friendships out of hand, more often than not attempts to do so were more likely to generate boredom than friendships:

I have been to meetings at the disabled living centre....I always got put off by those types of things where there would be a whole pile of people sitting around and saying "oh and what level are you" and "what happened to you?" and this and that and not just a social type of thing....[paraplegia] doesn't mean to say that I only have to stay with people in wheelchairs....I am not against having friends that are in wheelchairs [but] I am not going to go and sit in some place ...to try and meet them. (f,23,4)

Then again, those paras who had become part of their local disability community felt rewarded in many ways. Helping to organize events and mixing with more severely disabled people helped them to get their paraplegia in perspective: '...it opens your eyes to how well off you actually are' (m,20,4).

Paraplegics stereotyping paraplegics

I found it both surprising and paradoxical that the paras I spoke to tended to apply stereotypes to other paraplegics while strongly protesting 'normal' society applying the same stereotypes to themselves. This paradox is partly explained by the fact that the vast majority
of paraplegics felt no need or obligation to maintain contact with other paras once discharged from the Spinal Unit. As a consequence both paras and 'normals' are trying to understand a group with which they have little or no contact: both must resort to stereotypes when discussing paraplegics in general. The paradox is also partly explained by residual memories of the Spinal Unit's ideal 'successful' para which are, in turn, fed by a media which lionizes victorious para-sportspersons returning from overseas meets. Eventually, a stereotyped view of how other paraplegics do and be is all that the isolated paraplegic individual has to compare self with.

In the following quote an older para talks about the effects the disability stereotype has on self-perception and his consequent tendency to still avoid public space - after five years! He then slips into stereotype when talking about the wider paraplegic community:

... the image that paraplegic is shit country wide....you get the old people who never saw anyone in a wheelchair unless they were like - I call them "diseased cases" - that since birth. Those were the only ones that they saw and they have got that image in their mind which is probably the worst image that they can get. I haven't got anything against those blokes but they are very slow to talk and they kind of slow moving which means that it is passed on. You know, "look at the funny joker over there in a chair" sort of thing which makes an actual paraplegic stay at home, which I am, or join together in little clubs and that type of shit....the total image of a paraplegic in New Zealand is that there is something wrong with the brain....(m,17,5)

He expands on the stereotype, developing it in such a way to portray his staunch ordinariness in the best possible light. His comments on media representations of what it is to be paraplegic capture the essence of what other paras had to say on the subject:

...you go to the city any day you go down the street you go into the pubs you go anywhere and there are none to be seen. They are all pushing this bloody disabled whatever they call themselves. This sports thing over there where they all get together and chuck javelins around and look at us we can move faster than anyone else. And the media take that this is a good paraplegic ...he can do the 200 metres in x amount of time. They don't look at the other ones ...people like myself. They don't say, "look he has made a success of his life. He works an 8 hour day, he goes pig hunting he does this and he does that". They are more interested in the pinnacle type....When I first got out here people were saying, "oh what sports are you going to get into?" You say "fuck sports. I am not interested". I played basketball for a while. It was probably the worst experience I have ever had. You have got all these blokes running around saying how good they are and did you see me on the court today? and did you watch me? and you think what am I doing here? (m,17,5)
There are two interesting aspects to this quote. The first is the hostile rejection of the ‘super-cripp’, high sports-achiever, image of paraplegics as portrayed by the media. In a way this is a very devaluing image because not all paras can, let alone want to, become good at sport. Yet it has become a popular, totalized image of what a paraplegic can and should do and be. Comparisons are constantly made with the current hero(s) and if one is perceived as not trying to emulate him or her then self, character is called into question. The second, is the way in which some paras are complicit in the creation, in prolonging, and legitimizing stereotypes which cast paraplegics as constituting a closed, mutually dependent, nay, co-dependent, community that turns around sport and club-like activities. These were paras who could not ‘hack’ it on their own, be regular guys, do normal things like holding down a job and socialize with normal people; all-in-all pretty sad cases. By implication, the para expounding the stereotype was, when compared to these caricatures, doing just fine, was well adjusted, a ‘successful’ paraplegic who had not succumbed to his paraplegia, was out and about doing things with his (normal) mates.

A paraplegic community: real or imagined?
The foregoing begs two questions: does some overarching community of former Otara Spinal Unit paraplegics exist in reality? if so what form does it take? From the evidence presented one can conclude that if a paraplegic community is said to exist, then it might best be described as a moral community of interests. The moral component is shaped by a shared site of indoctrination as to what constitutes a ‘good’, a ‘successful’ paraplegic while the shared interests are generated by a shared corporeality, the paraplegic body.

Imaginary paraplegic communities do exist mainly as stereotype in the minds of the media and the non-paraplegic community which reads, listens to, or views the various media. This is not to deny that some paraplegics are committed sportsmen and women but to point out that they do not constitute a real sporting community to which most paraplegics belong.

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9 When I was first paralysed Eve Rimmer was the darling of the media, collecting lots of medals whenever she competed. I was constantly asked if I knew Eve, what my sports were, why I was not into sports? Since Eve there has been a succession of media stars: Robin Courtney, Neroli Fairhall (Gold in Archery) Jenny Newstead (golds & silvers in swimming, Barcelona Olympics, 1992) Cristeen Smith (gold in sprint, Barcelona and lionized by Paul Holmes), Ben Lucas (bronze in marathon, Commonwealth Games 1994).
Another imagined community exists in the minds of some paraplegics who, in their loneliness and isolation, constitute themselves as staunch individuals who do not need the support of some pathetic, paraplegic community which they 'know' exists out there somewhere.

SUMMARY AND CONCLUSIONS

In this chapter interactions within the personal and public spaces of paraplegics have been examined for their effects on the subject. In terms of personal interactions, where family and friends were accepting and supportive, the integration of paraplegic body and self is positively facilitated. Many of the paras in this study reported negative reactions from former friends. This hurt quite deeply and was reflected on with a mixture of bitterness, confusion, understanding, and sadness. However, at the time it did tend to goad the paraplegic on to establish his or her own reality as an independent subject.

When it came to play/leisure, there had been a shift from active to largely passive pastimes. For a majority of paras this narrowing of leisure options was accompanied by feelings of frustration that they now had to accept second best. These feelings of loss were offset for most by the fact that they still enjoyed their leisure time, only differently. For a minority however, paraplegia has meant such dramatic changes in their leisure activities that they now feel reduced as people and socially isolated.

Contact between paraplegics is very limited following discharge from the Spinal Unit. Any 'paraplegic community' that does exist, exists more in the imagination as a moral community underpinned by shared corporeality and codes of behaviour. Since 1972, however, all traumatic paraplegics do belong to another community which is real, namely, the Accident Compensation Commission (ACC). Their experiences with ACC are discussed in the next chapter along with the levels and sources of income and the value of the paraplegic body on the labour market.
Chapter VIII
SOCIO-ECONOMIC ASPECTS OF THE PARAPLEGIC BODY-SUBJECT

In this chapter it is argued that the separation of the economic from the social leads to totally erroneous conclusions when discussing human ontology. That humans are both social and economic beings is manifestly true for the modern urban dweller where physical survival and the ability to participate socially are largely determined by economic circumstances: the basis of life - shelter, food, clothing, education, recreation, entertainment - must be purchased. Moreover, income is obtained in a social process which has consequences in terms of individual consciousness/subjectivity as a product of purposive productive activity (Marx 1976, 1977, 1980), and in terms of social standing.

When paralysed a whole range of extra costs are imposed on income. The most obvious include the purchase and maintenance of reliable motor transport, regular visits to the doctor for medical supplies, prescription charges, added wear and tear on clothing and shelter, having to employ tradesmen to carry out repairs and maintenance formerly carried out by the non-disabled home-owner, and so on. Adding to the difficulty is the likelihood that the individual can no longer continue in the paid employment s/he was doing as a non-paralysed person. For those injured through some other person's fault, litigation for monetary compensation was, albeit chancy, a solution; for those paralysed through their own fault welfare was the only solution. More importantly, compensation was always more generous because one could sue for the loss of enjoyment of life as well as the extra costs of paralysis. By comparison welfare was niggardly because it only (and barely) covered the latter.

Legislation to remove the chance and inequalities associated with litigation for accident compensation was enacted in 1972. The Accident Compensation Commission Act institutionalized arrangements for the granting of compensation and income maintenance to anybody (citizen or visitor) who suffers personal injury through accident while in the country. Following their accidents, most of the paraplegics in this study were immersed in the bureaucratic machinations of the Accident Compensation Commission (ACC) as the state fulfilled its statutory obligations to them. Their reactions and resultant perceptions of the way the state views (their) paraplegia are outlined in the first section of this chapter. The level and sources of income of the paraplegics in this study are then examined followed by a section on their experiences in the labour market.
THE ACCIDENT COMPENSATION COMMISSION

In a particularly enlightened piece of social policy, no fault accident compensation was provided for all New Zealanders with the passing of The Accident Compensation Act 1972. Provisions were amended and extended by the incoming Labour Government in 1973. Accident Compensation had the aim of enabling the recipient to maintain his or her previous standard of living and was to be funded from levies paid by employers that were calculated on their total wage bill. Being no-fault compensation all injury by accident was covered regardless of the circumstances of the accident. As a trade off, New Zealand citizens gave up the right to litigate for accident compensation. Accident compensation must, therefore, be seen in a totally different light from that of social welfare: it is awarded on the basis of one criterion - injury through accident. Unlike welfare, it is not means tested, it is granted on the basis of need not status; in theory there should be no stigma attached to collecting accident compensation.

The Act provided for a one off lump sum compensation for loss of enjoyment of life (up to $10,000) and loss of function (up to $17,000) and earnings related compensation (ERC) of eighty percent of what a person was earning at the time of his/her accident for the period of rehabilitation. For severe and permanent disability ERC was on-going. The paraplegics I spoke to were given three years of ERC. If they found employment which did not pay as much as their previous job, ERC would provide a 'top up' to make up the difference. The Act also established the ACC with responsibilities for rehabilitation, any necessary home alterations (up to $40,000), the provision of aids and appliances, and liaising with other agencies in the field.

While it is fine in theory that an accident victim will get adequately compensated as of right, and that, because ongoing compensation is earning related, it will not be stigmatizing in any way, the question that remains is: does it work this way in practice? In the rest of this section the questions of adequacy and accessibility of ACC as well as the effects of receiving ERC on self-perception will be addressed¹.

¹ *Mutatis mutandis, the comments* (p.129) *on how the critiques of the Spinal Unit should be read, apply to the accounts which follow on the ACC, the welfare bureaucracy, and income support which also have implications for policy. Again, the tension is between the ways in which paraplegics were experiencing their bodies and selves as subjects and the regimes of surveillance, discipline, and normalization that their bodies were subjected to by these institutions.*
ADEQUACY OF ACC

There are two aspects to adequacy: the first relates to the amount of lump sum compensation and the second, to the overall compensation package including home alterations and aids and appliances.

ACC: adequate lump-sum compensation?

About one third of the paras I spoke to felt adequately compensated (Table 4.0:291), but only in terms of the regulations. And even then the amount was always qualified: 'Compensation has been within the terms of the Act. But money never gives you back your previous abilities' (m,31,5.5), captures the tone precisely.

The overwhelming majority, however, felt hard done-by in the lump sum payment they received from the ACC. While it was generally recognized that no amount of money could adequately compensate - 'Pain and suffering and loss of pleasure can never be gauged by referring to a text book for a dollar pay out' (m,32,6) - a frequent complaint was about the lump sum received relative to lump sums received by others who had sustained less serious, non-permanent injuries:

... they are paying pricks, who are trying to escape prison, $18,000 because he will walk with a limp for the rest of his life and they are jumping up and down and saying we can't pay you. You have got to have medical evidence before we are going to give you $17,000. I mean, fuck it! Their priorities are all up the shit. (m,17,6)

What especially rankled this para was that not only had lump sum payments gone up since he had been paid out but that the person in question was injured while engaging in illegal activities. Moreover, this para had been subject to endless bureaucratic hassles in getting his home alterations done and still had to produce medical certificates certifying that he was still paralysed whenever he claimed anything from the ACC.

For others, the inability to undertake civil action for compensation was an issue. One woman touched upon this when stating how meagre the compensation was in light of her injuries and in light of what she might have received through litigation:

I ...feel $17,000 bought me a car and that replaced my car. Basic car I suppose. And put a deposit on a section and that was it. If I could have sued a negligent driver I would have had a big pay out but at the moment I'm struggling. We're struggling because of the extra costs of my disability which I haven't been compensated for.... (f,26,10)
ACC: fair deal overall?

A small majority (Table 4.1:291) thought that overall they had got a fair deal from ACC:

I have nothing but praise for ACC. (m,37,8)

The people from ACC were lining up to help me. (f,25,6)

Often the praise was qualified: the compensation was hardly generous but it was better than nothing:

I don't think money compensates for loss of body function. However, without their help and payments it would be far more difficult. (m,24,1);

I don't have any real grizzlies with ACC as life could have been worse. (m,29,8)

Others were totally dismissive:

ACC are just a big bunch of pricks. They buggerized me around right from the start....They didn't want to pay me a lump sum they held that up ...they have just been real arse-holes about everything....They wouldn't give me what I was entitled to....Anything I wanted I had to fight for it was just an endless battle. (m,17,6)

They turn my stomach: never have I disliked an organization more. (m,20,6)

I'm pretty hostile to ACC....They're really bad....At the time I couldn't get nothing out of them. This [rehabilitation officer] ...was treating us as if it was all his money and that he shouldn't give anything out or do anything really. (m,21,6)

It is interesting to note how attitudes on the lump sum payment varied with attitudes on the fairness of the deal. Only thirty-four percent thought it an adequate amount as compared with fifty-eight percent who considered that they got a fair deal overall from ACC. This suggests that contained within the institutional arrangements for compensating traumatic paraplegia are contradictory messages about the social value of paraplegia. For some, the message is that while society places a low monetary value on their paraplegia the institutional support is quite generous in getting them back on their feet in civil society: 'Whenever I wanted something, or had something to say, they listened and did what they could' (m,23,4).

In contradistinction, another group perceived the lump sum as a bit of a windfall but was dismissive of the on-going support offered by the ACC. The source of much of this latter group's dissatisfaction can be traced back to their dealings with functionaries within the bureaucracy, the penny pinching and mean spiritedness of the institution:
I only achieved a reasonable level of compensation by knowing the Act and fighting for my rights. I ended up winning 80% of all appeals for items declined by ACC. (m,31,5,5)

In some cases it was not just a matter of fighting for statutory entitlements, it was a matter of knowing what one was entitled to and then fighting for it:

They pay for a housekeeper three hours a week. Which I had to fight for. I only found out after eight years that I was entitled to one. They don’t actually tell you I don’t enjoy it having to beg and grovel. I really don’t. (f,26,10)

The not enjoying ‘having to beg and grovel’ from ACC was a point many returned to time and again. The pleading and battling for statutory rights not only left many physically and emotionally drained (‘It was really difficult. If my parents hadn’t have been the fighting sort ....’) it also sent out contradictory messages about the person’s status and the quality of ACC vis-a-vis other welfare benefits. The impact of these messages on self-perception is examined below.

As I travelled around the country it became clear that the perceptions of fairness of the ACC deal depended upon a number of factors other than size of the lump sum. The sensitivity and sensibility of their rehabilitation officers, the co-operativeness and speed with which home alterations were completed and wheelchairs prescribed and delivered, the ease with which negotiations for ERC were completed and was subsequently adjusted to keep pace with inflation or wage increases over time. These were all factors in the ‘fairness’ equation.

Perceptions of unfairness were underpinned by experiences generated by the arrogant and, seemingly, uncaring approaches adopted by some rehabilitation officers who showed no flexibility in the application of petty bureaucratic rules. These paras felt cheated and humiliated by a system which was purportedly designed to assist their rehabilitation. Instead they were made to feel greedy and grasping by functionaries within a bureaucracy which did not recognize the extent of the emotional and material costs involved in living paraplegia. This was not always the case, however, as experience and, hence, perception varied from region to region and from one rehabilitation officer to another. Ultimately, however, perceptions of fairness are formed over time because living paraplegia occurs over time. The accessibility of services, the renewal of aids and appliances, or their replacement with technologically advanced models, thus, becomes an ongoing concern, an ongoing index of fairness, an ongoing imposition, and reminder of status.
Accessibility

As already indicated, a small minority of paras had experienced no problems with accessibility to services: ACC officials 'lined up' to help them. But such comments were exceptions to the rule of red tape, legalistic interpretations of regulations, and bureaucratic delays. For most, these obstructions began at a time when they were most vulnerable, that is, soon after the accident when they were learning about their changed bodies and how to live them, when they were bursting to get out of the Spinal Unit and back into the real world and normal life, yet, were, perhaps, a little fearful of what 'normal life' might now mean. Obstructive bureaucracy just added to the emotional turmoil. Take the experience of this para in trying to get his lump sum compensation:

Mum and Dad had set up a trust with a local accountant...because I was under age and they [ACC] said no they wanted to put it under public trust which don't pay any interest. And Mum and Dad were going to stick it in this interest account and so they...held up for a long time. (m,17,6)

Such behaviour on the part of ACC had the effect of constructing the institution as punitive and controlling in the mind of the paraplegic concerned. Other paras experienced all sorts of delays (home alterations are discussed below) with the end result being that ACC became oppositional to their getting on with life. The underlying message was: your body has changed, you are redefined as inferior and dependent, and you will do as you are told. And while house alterations, specialized equipment, earnings related compensation and a variety of specialized services all eventually get sorted out, that is not the end of the story or, for that matter, the end of paraplegics being told who and what they are, of being measured, monitored, certified in terms of their paraplegic bodies. Life and social being is changed irrevocably:

Oh man...they [ACC] get on your back...they really crawl all over you...they suck...like...OK it's a new office down here and they've got new staff and that and OK they've been educated and all that sort of shit and that. But everything...just goes round and around in circles....I ordered a...water bed and a new wheelchair - I need one you know cos my backside [pressure area] and that - she goes OK. And that was in May [now December]....She says you have to have a doctor's certificate. So I went to the doctors and then come back and she goes no you can't, you have to have an orthopaedic surgeon. Like they run you around, you know. To get a wheelchair, I have to get a wheelchair therapist....and she came out and measured me up...and she wrote...I've got the measurements here for his chair but I recommend that he has - I don't agree with him having a fixed foot plate ....Which is a lot stronger to me you know with my weight and that so....That's another thing about ACC. They know what's best for the person, chair wise and that sort of
thing. What's best for the car, even the OTs - best for the car and the bed. Everybody's different, you know.

... you've got to fit into their conceptions?  
Yes. Like they bring you out a chair and this is your chair, you know. Sit in it. This is going to be your chair for the rest of your life, you know. Unless you get another one .... you go through all the horse shit and that. And you get so close and that sort of like got to wait and sort of on the edge. Then it comes through, you know. It's really like hanging on an edge.  

Contingency of body is paralleled, reinforced, sustained, supplemented, concretized by contingency of social services. One is left 'hanging on the edge' of an uncontrollable vortex of institutional arrangements which are central to living a paraplegic body. Accidents may be moments of fate but it does not follow that traumatic paraplegics necessarily become passive and fatalistic about life or totally subservient to the institutions designed to serve them. There are always opportunities for and moments of resistance. The paraplegic previously quoted continues, relating the exchange that took place when he was introduced to his new rehabilitation officer:

... like I shook her hand and ...said 'how are you going' and all that. And I says, 'I suppose you've been through all that training they go through for the rehab officer and that.' And she goes, 'Yes. Just done it not so long ago.' And I said, 'Oh yes. and [you] only need to learn one word.' And she said, 'What's that?' and I said, 'No.' And she goes, 'What do you mean?' I says, 'If I ever ask you for anything you just say, "no"'. I used to rub it in to them ....

This is like shooting the messenger when one does not like the message. Notwithstanding, the functionaries of the system do present immediate targets for some off-loading of the many frustrations that accrete to the paraplegic body. One point of frustration is the limitation placed on being that result directly from the denial of perceived statutory rights coupled with the loss of income and earning power that is experienced by many paraplegics.

INCOME: LEVEL, SOURCE, AND SELF PERCEPTION

Earlier the question was posed whether the thinking which postulated that ERC would be perceived as less stigmatizing than welfare was correct. During the course of the interviews I was surprised to discover that many of the paraplegics who were receiving earnings related compensation perceived it as equally demeaning as welfare. These paras made little
distinction between being on ERC or on welfare: they were on income maintenance and this had important consequences for life style and self perception.

Sources and level of income
The most obvious effect of shifting to income maintenance is a decline in level of income. ERC is set at eighty percent of earnings in the twelve months prior to the accident and welfare at a level to just maintain life, to encourage recipients to return to the labour market.

Income was derived from a variety of sources (Table 5.0:291). A little over one third earned their incomes in the form of wages and salaries with a small minority having their wages 'topped up' by ACC. Most paras have their income sourced from ACC. Moreover, almost two thirds are dependent upon either the state or, in a few cases, their partners. Over seventy-five percent of those who experienced any change in income, reported a loss (Table 5.1:292)

Income losses were calculated assuming the same job, the same amount of overtime being available, wage rises, and the pay increments that would have come with seniority and promotion. For those on a benefit, the absolute losses were obvious when compared with theoretical levels of income. By comparison, decline in income for those paras who had returned to work were real. One para explained the loss of income he suffered when he returned to a new job he could do as a paraplegic at his former place of employment:

... I'm not doing shift work or ...[on] the same hourly rate but ...since my accident we've had whopping great pay rises [in previous job] ...fifteen percent that year....with ACC the increases are not on the same level....only had one and a half percent increase from ACC. In that way, whereas when I first had my accident and was on a bloody good stick [ERC], now in comparison I've come back to an ordinary person working at the milk company. (m,21,6)

For this paraplegic, his paraplegia means that he is devalued in terms of the job he does, in terms of what he earns, and in terms of the status he derives from his occupation. Reasons as to why one would accept inferior pay and working conditions as a paraplegic are explored in the section on the labour market.

Significant income losses were experienced by about seventy-five percent of those I spoke to. Just under a half said that their life styles and standards of living had been affected
negatively by these losses. Some, in this category, reported a subsequent decline in how they perceived themselves in terms of being and social status.

**Decline in income: devalued self-perception**

A number of those I spoke to nominated income loss as an important factor in their loss of self esteem and subsequent devaluing of self.

For female paras, this diminution in being included feelings of isolation (a drop in income had translated into 'no social life') and in some cases depression (makes me feel 'terrible'). For males, negative changes in self perception were generated by, among other things, an inability to provide as well for the family ('I could have given the family a more comforting life style and living'), anger over how paraplegia dictates a lower level of earnings and smaller range of occupations, feeling trapped by a lack of qualifications and no longer being able to do the manual work that brought in good wages. The differences in how self perception changed seem to reflect the gender based social expectations of individuals rather than the biological-natural consequences of paraplegia.

Having an adequate income is not, however, of itself, a complete solution to negative self-perception because the source of income can be problematic. Moral judgments are inferred from the way income is obtained: it is more 'moral' to be employed and to be earning one's own income than to be receiving a welfare benefit from the state. Beneficiaries are, thus, largely characterized as 'bludgers' who rely on the state rather than themselves to do an honest days work in the cause of self-sufficiency. Now, whilst those on ERC may not fit the classic description of 'welfare beneficiary', many felt that way for a variety of reasons. The most frequently voiced reason was that they were made to feel like 'welfare beneficiaries' and/or 'bludgers' by ACC officials who continually pressured them to find a job, to 'get off ACC books'. This external pressure was reinforced in most cases by their perceptions of their own capabilities, by their own prejudices, and by social prejudice. First, all perceived themselves as being fully capable of work but 'unemployed' because of the social stereotyping associated with the disabled. Notwithstanding social prejudice, they still experienced themselves as fit and healthy individuals and, thus, they also experienced the social and moral pressure for such people to be employed. Finally, there was the tendency, coupled with that of the wider community, not to differentiate between ERC and other benefits; all income maintenance is seen as a drain on the 'taxpayer', all are 'welfare beneficiaries'. Finally, the most bitter of ironies was that many of these paras viewed with
contempt those in the category 'welfare beneficiary'. As former workers their own prejudices remained against people capable of work but who chose to, 'live off the state.'

... I wanted to go back to work and still feel like I was doing something with my life....[On ERC] I felt like a bludger ...everyone is entitled to it but if you can do something and you have got the means to do it then you should .... (f,23,2);

To summarize, the majority of paras on income maintenance hated being cast as beneficiaries. They had absorbed the social stereotyping as 'dole bludgers' and felt demeaned and devalued by not working for their money as well as trapped and frustrated by their circumstances. In contradistinction, a minority felt no qualms about accepting ERC. They saw it as their legal entitlement; their right to sue for civil compensation had been removed by statute and replaced with state compensation. Members of this group vigorously rejected any stereotyping. The minority view did not, however, amount to an endorsement of the level of income maintenance. Indeed, many felt trapped in a kind of limbo where life was maintained but purposive productive activity denied: 'on a benefit ...you can survive but you can't do anything' (m,19,12). If this was the case, what effects did income maintenance have in shaping attitudes towards paid employment?

**ERC/income maintenance and attitude to work**

Of those who responded to the question, just on two-thirds (Table 5.2:292) said that getting ERC or a benefit had not changed their attitude towards working. For some, the thought of being on income maintenance for the rest of their lives was unthinkable. ERC has its place during the early phase of rehabilitation but after that few planned to 'sit around on a benefit at all' (f,26,10). Another group felt that ACC was a positive incentive to get work as it was such a small amount and because of the pressure officers put on them to find work and to get off ERC. Others pointed out ways in which ERC and/or benefits acted as a disincentive to taking up paid employment.

Some saw it as creating dependency:

I think you can sort of like get attached to it...I know people who like, they don't go to work. They don't find jobs because they know they can go on ACC for the rest of their lives. (m,15,10)

Of the same order, were those who were, in a sense, trapped on ERC. These paras had formally been employed in high paying jobs and now got more on ERC than they could hope to earn as paraplegics: 'It doesn't hurry me back to work 'cos I'm getting good money. And
I can't really afford to lose that at the moment because I've got debts to pay. And it doesn't pay to get back to work in a hurry because I don't think I'd be earning as much as ACC is paying' (f,21,1.5)

A major disincentive to taking up paid employment was the belief that paras only got one chance at ERC and that they blew that chance for all time once they move into employment. One para spoke of the conventional wisdom regarding ACC when he was in the Spinal Unit:

I was really looking forward to going back to work and I was always told [by visiting paras] while I was at the Spinal Unit, "don't go back to work. It doesn't pay to work. ACC penalizes you." [Now] I firmly believe ACC does penalize you if you work. You're better off not to work. But I could not work. I'd go mad. I enjoy it. (m,21,6)

Finally, reasons for not moving off ERC into paid employment included the limited range of occupations available to them as paraplegics, the (mainly) unqualified and unskilled labour they had to sell, the impracticality of working conventional hours given the extra time it took to complete their activities of daily living, and the difference between what they could earn and what they received on ERC was not worth the extra effort involved in getting to work. For those working and getting a 'top up' from ACC, the rate at which this would abate removed any incentive to work harder for promotion and increased salary.

Perhaps the biggest disincentive to entering the labour market is the 'security blanket' effect of income maintenance:

... it's funny how the system traps you. You think that it's real cruisey being on a benefit, you get a cheap mortgage, you get a half price phone, insurance so that stops you from getting out and working really. To actually do better ...you've got to be earning about $500 gross a week at least when you add up all the benefits that you get by being in a wheelchair. You know you get loans and you get suspensory ...you sort of get on to a sort of a cruisey state where life just is monotonous ....I'm trying to shrug off this social welfare side of me of life and get into working. But I'm really quite paranoid about taking this step too [because] I lose the security blanket of the cheap mortgage and a regular income....So that's a psychological barrier for me to get over the fact that I'll be working and having to put in the effort and get up and do stuff and I won't be really getting any gain. (m,19,12)

In the above discourse the seductive side of income maintenance is clearly articulated. It is the invisible benefits - the cheap loans, the cheap insurance etc - which are so entrapping and which mark social welfare from ERC. ERC is generally more generous than welfare and
the additional benefits are an attempt to equalize conditions between the two groups. But, 'all the benefits you get from being in a wheelchair' have an effect similar to that of wrapping the paraplegic body in a cloying, protective cotton wool. It is this very coddling which is slowly choking this particular subject to death, which he finds so destructive, so demeaning, so controlling in terms of the criteria which must be met. In this sense, the 'security blanket' is revealed for what it really is: institutional control of the anomalous body, another layer of paralysis.

Clearly, income maintenance is a double edged sword for paraplegics. On the one hand it saves them from complete impoverishment. On the other it confirms their status as dependent and unemployed, a status few would freely chose. After a while the novelty of not working wears off and the days become long and boring. The end result is that many feel they are leading lives of uselessness and, combined with other aspects of their paraplegia, begin to feel quite worthless in themselves. The imperative to be in meaningful, paid employment is compelling. However, two questions remain: how receptive is the labour market to the paraplegic body? In what ways does the labour market experience shape subjectivity?

THE LABOUR MARKET AND THE PARAPLEGIC BODY-SUBJECT

Marx's thesis that consciousness is formed/shaped as humans labour to transform the natural world to meet their individual and social needs was largely confirmed by this study. In capitalist Aotearoa/New Zealand the norm is for most people to engage in this transformative process as wage labourers (see Chapter I). Hence, it was not surprising that, almost without exception, the paraplegics in this study stressed paid employment as an important factor in how they and others now constituted them as subjects. Again, this is quite understandable given that in the twelve months prior to their paralysis eighty-five percent had been in full or part-time employment (Table 6.0:292). In this section their experiences of finding paid

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1 A number of the paraplegics in this study were paralysed while overseas and did not qualify for ACC. Instead they qualified under the Disabled Persons Community Welfare Act 1975 for the Invalid Benefit and, providing they met certain criteria, a Disability Allowance, suspensory loans for purchasing a motor vehicle if they were in employment and not receiving a benefit. Before the State Insurance Company and Telecom were privatized they offered cheap insurance and phone rentals to beneficiaries.
employment as paraplegics, working and the meanings they attach to work are examined in terms of the effects in creating the subject.

**Finding paid employment**

**Exclusions**

During the interviews it became clear that paraplegia had inscribed on the subjects' bodies a high rate of unemployment. This pattern was later confirmed in the survey. Overall the unemployment rate was forty percent compared with seven percent of their non-paralysed bodies (Table 6.2:293). This is understandable for those paras who were previously employed in unskilled, skilled, and semi-skilled blue collar occupations involving a high degree of mobility and manual labour. Frequently, however, the reason for the high rates of unemployment was to be found in a stereotyped reading of the paraplegic body. Many paras could only explain their job-refusals on this basis. One recalled his experience of this when he first started looking for work:

...I rang up and they said "come in for an interview" and I said "oh, by the way I'm in a wheelchair" and it goes "sorry the job wouldn't be suitable" and that - you know. I rang for four days and I just got sick of it... (m,15,10)

In terms of frequency, the 'not being suitable' syndrome was closely followed by, what Michael Oliver (1981:50) calls, the 'psychological imagination' of employers. Here the employer imagines how helpless and incapable s/he would be if confined to a wheelchair and refuses to employ the para. This is particularly galling. One paraplegic, who was capable of getting around on crutches, explains:

... as soon as they see the crutches they've already got "no" in front of their eyes. They seem to be very biased of somebody that's got a disability. (m,21,2)

Expecting to be rejected on the grounds of being paralysed, of not even been granted an interview, a number of paras adopted the strategy of not telling prospective employers the awful truth. A former physical educationalist recounts his first interview:

... I didn't tell em I was in a wheelchair - it was quite funny seeing the looks on peoples' faces....but they'd ask me how much experience I'd had in a wheelchair [as a community recreation officer] and I knew I'd missed out on the job after that line of questioning. They didn't want to employ me because of my paralysis. (m,27,7)
One woman, highly qualified in terms of relevant tertiary qualifications and job experience, discovered that, as a paraplegic, her body did not quite fit:

... people won't hire me because ...I'm a para....One person was honest enough to say "we don't think we can hire you because you're not in keeping with the image that our firm wants to project." (f,22,1.5)

Another woman who was a teacher at the time of her accident recalled:

... I had a hell of a fight to get back. The general manager of the ... Education Board ...said, "We're not having people like that teaching." (f,26,10)

Then there was the problem of being a disabled body in a world designed for and by non-disabled bodies. Access to and within buildings, the extra hazards associated with fire risk etc., were frequently cited as impediments to employment. The following comment is typical:

... they have no idea of the access needs of paras. I'd go along for an interview and there'd be a flight of stairs to go up. At another I got into the building but then couldn't get to the machine. (m,21,3)

After a few rejections on the basis of accessibility, some paras could not help but feel that architecture was a convenient mask for prejudice. For example, a previously unmentioned flight of stairs materializes as soon as the prospective employer learns of the wheelchair.

Keeping in mind that all the paraplegics insisted they applied for jobs which they knew they were physically capable of doing, how might the negative employer response be explained? Using Marx's analysis of the logic of capitalism and the use of wage labour as a source of profit, then clearly the paraplegic body must be perceived by the capitalist employer as not being as capable of producing as much surplus value as an able-body. But, because under capitalism the social relations of production remain fetishized, some employers revert to disableism, the ideology which casts disabled people as dependant and unproductive, to justify their non-employment of, in this case, paraplegics.

As opposed to Marx's materialism, Merleau-Ponty's theory of intersubjectivity provides another explanation. From this perspective, a disjunction could be said to be occurring at the corporeal schema level; an irrational fear of the unknown grips the employer who refuses to employ the paraplegic. 'Protecting' the feelings of staff already employed may also be advanced as a rationalization for not employing the 'cripple'.

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Understanding of the situation is not advanced by arguing for one position over the other: the gut fear of disability and disabled people is supported by the misapprehension that the paraplegic body is always less productive. The end result is that the paraplegic is refused employment. Some of the paras in this study interpreted this refusal as a broader, societal rejection of them personally. It also meant the imposition of an unwarranted subjectivity which cast them as incapable, useless. Materially, it made them dependent on the state for income maintenance; psychologically they had become ‘bludgers’ and they felt downgraded, cheapened, worthless. When asked how he felt about being out of a job, one young man replied:

Stink. I feel like I am abusing the country. I feel like I am using everyone else. (m,17,5)

Acceptance
In contradistinction, not all paras had had negative responses from employers. Whilst some were between jobs at the time of the study, over half had found employment as paraplegics (Table 6.1:292). Of these, the majority had returned to their previous places of employ, where they said they were treated with sensitivity and fairness. Others had successfully found employment in a variety of occupations where their paraplegia made little or no difference to job performance (Table 6.3:293).

Overall these paras had positive experiences in seeking employment. One recalled, ‘...I’ve never been knocked back in a job yet.’ (m,15,14); another, ‘I had a job interview and they offered me a job and I became a stock clerk’ (m,18,14).

To avoid any embarrassment or overt discrimination, a number had their first job interviews arranged for them by their rehabilitation officers, through work schemes, or by a family member:

...I got it through my father....the guy [employer wanted] ...extra people ...and my father said, “My son’s looking for a job ...oh he’s in a wheelchair.” He says, “Oh bring him down. Give him a try out.” So I went down ...and when I went in there he ...shook my hand and made me feel really welcome. (m,15,10)

The above quote captures the spirit of the various reflections on the meaning paras attached to being productively employed. For a start they felt valued and socially integrated; they were proving to themselves and to the rest of society that they were capable of looking after
themselves, and, by so doing, were contributing to the common weal. More importantly, the mere fact of having a job, of being productive, provided a sense of continuity with their former non-paralysed body and self. This is not to deny the fundamental sense of discontinuity that many paraplegic body-subjects experienced back in the work place.

**At work**

The major worry for most of the paraplegics that returned to work was to be regarded equally as a worker by their co-workers rather than as a disabled person who was expected to perform below par and for whom allowances would be made. They wanted to be treated as normal, capable and productive workers. But the bald fact was that they were paralysed and that they were in a wheelchair and that social perceptions of them were inherently negative and disableist; in short, they had to prove themselves. Almost half of those who had worked as paraplegics felt this way, at least initially (Table 6.4:293). One explained:

... [other workers] were a bit hesitant to start with until you proved yourself but after that they were as good as gold....as long as you aren't lagging behind....the main reason that you have to prove yourself [is]...because you are a para and you have to prove to them that you are as capable of doing it as they are. (m,17,5)

But it was not just a matter of proving ability to other workers, it was also a matter of testing, proving self:

...you certainly do feel that people are watching you to see how you're coping....Not pressured particularly but I think within myself I had to prove that I could do it....I knew I was perfectly capable of doing the job. Just get in and go and show them really....I suppose you really do have to prove far more than anybody else. (f,26,10)

The most striking thing about those two quotes are the references to the ongoing scrutiny, being subject to the normalizing gaze of fellow workers. Whilst the judgements and evaluations might be mutual and equally apply to all workers, the paraplegic subject feels even more so precisely because of his/her body. One ruefully observed that paraplegics, 'have to work three times as hard to be considered a third as good.'

However, the 'proving yourself' syndrome was not universal. Some paras were naturally cocky and self-assured:
...I'm a confident person so I never felt I had to prove myself to anyone ...I've never done that and I wasn't about to start ....I was just like anyone else. I looked at it from that point of view. (m,19,12)

One woman (23,2) spoke at length about the difficulties she experienced on returning to work as a paraplegic.

**The double disadvantage: female and paralysed**

This woman worked in a small rural town as a linesman for the telecommunications section of the Post Office. At the time of her accident she was already in contravention of local mores: not only was she the family breadwinner (her house-husband was principal care-giver for their young son) but she was also studying extramurally for a certificate in electrical engineering. She is quoted at length:

...with the job that I had it was quite hard because being a woman you don't have to be as good as, you always have to be better. And there was a lot of resentment from me being there in the first place. Because I was the first female to be had taken on in the district. And I was always telling myself I could do it, and do it well. And I did very well in my exams an' that....it sort of almost backfired to my way of thinking. Me having an accident and people saying "well you shouldn't have been there anyway" and that type of thing.

...they always admit that in someone's career they expect to fall off two or three times. It's not many people who haven't canned off a pole...but they forget about that when it comes to me "I shouldn't have been up there!"

After been discharged from the Spinal Unit she returned to take up a position as a technician in the workshops. However, she still:

... felt a bit uncomfortable working back there because I was still working with other guys and they sort of avoided you like the plague...maybe its just being a para - the woman that worked there and my immediate boss - he was really good....But the others, I don't know whether I was a constant reminder to what might happen to them or what it was? But, umm, I didn't really enjoy working there any more ...because a lot of them felt I shouldn't be there anyway, you know. I'd had an accident; I should be at home now ..."Why aren't you on ACC?"; why did I come back to work? - A man could have this job! That was only a very small minority but up there they have a pecking order, those that make the most noise tend to dominate, so their opinion..... (f,23,2)

This debilitating mix of sexism and disableism resulted in this paraplegic taking severance pay when Telecom was preparing for privatization in the late 1980s. In small town, rural New Zealand this woman was punished for being completely other. In a world dominated by men and physicality, this woman broke all the rules: her body lacked both penis and movement.
Moreover, she was smart. Her paralysis was the final straw, the straw which broke the camel's back.

In contradistinction, most paras found their co-workers helpful and considerate. While this was never embarrassingly 'over the top', co-workers were generally prepared to walk that extra mile: ‘...people would just about go out of their way to make sure you got what you wanted or would help you in some way’ (m,19,8).

**The tyranny of the ideal**

Within the Spinal Unit residents quickly learned that a prime, if not the prime indicator of being a 'successful' paraplegic was to be in paid employment. The message was embedded in three alternatives within the vocational rehabilitation programme. First, if possible the patient is readied for return to his/her former job with the ACC rehabilitation officer negotiating with the employer over hours of work\(^2\) and matters of access\(^3\). Second, if the former does not apply the rehabilitation officer endeavours to find appropriate work. Third, the patient is encouraged to undertake vocational (re)training.

Now vocational rehabilitation is in itself not a bad thing. But when the institutional imperative to produce productive paraplegic bodies (that is, 'successful' paraplegics) takes precedent over the individual needs of the subject, the results can be quite damaging. Take the example of the teenager who, at the time of his accident, loved his job of delivering goods for a retail firm. His employer subsequently offered him a job as a salesman which he was encouraged to take, even though he had never had the temperament suited to this type of work. Nevertheless, he took up the position immediately upon discharge. In the interim the firm had put in an accessible toilet, adjusted counter heights, had extra phones connected, bought another computer for him to use, and his new job was better paid. He felt welcomed and valued by the company.

These positive feelings quickly dissipated when the reality of what the work involved struck home. It meant approaching people in a highly public space and persuading them to buy

\(^{2}\) Some initially returned to work on a part time basis and gradually built up to a forty hour week. New jobs involving less hours were created for others.

\(^{3}\) Funds are available through ACC for making work places accessible eg ramps, accessible toilets etc.
goods when he had yet to persuade himself that he felt OK about his new, out of control, 'leaky' body. As a result he felt, 'scared stiff ... most of the time' (m,20,2). He continued:

... I use to get pretty snappy. And the staff knew that I wasn't handling the situation with the customers at all ....You can't really rush a person that's been through a helluva accident, realizing they're paralysed, into a work situation ....That's what the Spinal Unit was trying to push into you. Once you were out of the Spinal Unit you had to get out and find a job ...but I think you've got to sort your mind out first ....Sometimes I used to come home from work...in such a foul mood that I'd take it out on my parents when it wasn't really their fault.

Having not yet fully grown into, enselved his paraplegic body, this young man was thrust into the full glare of the public, put on show with the rest of the goods. In the pursuit of the ideal, relationships deteriorate and no one feels good about the situation, especially the man at the centre. That he was not yet ready psychologically to face the world was not surprising given the emphasis placed on corporeal rehabilitation to the exclusion of the psychological at the Spinal Unit (see pp. 246-50).

Super-exploitation

Earlier it was argued that the disabled body is not as valued as the non-disabled body in the labour market as a source of surplus. However, because of this it vulnerable and open to exploitation. A number of paras talked about the ways in which they had been exploited in the labour market. These included having to work the first month without pay to establish work credentials and then, perhaps, discovering that there was never any intention of hiring; having to work at lower pay rates than non-disabled workers; having to work 'three times as hard to be a third as good'. The following account raises some interesting questions:

...I was ...working for a replacement data firm ....I trained up this other girl - who was to relieve me if ever I had a day off - and they hired her [immediately and fired me] ... if there are two people...and one is in a wheelchair, it is human nature to want to ...if they are both the same qualified...hire the able bodied one. (m,20,4)

Leaving aside the duplicity of the employer, this quote is notable for its portrayal of the fatalism I found inherent to many traumatic paraplegics. It is linked to the ordering of the cosmos and their position within it at a given time and place: multifarious discriminations are now part of their karma which they must live out (see next chapter).
The meaning of paid employment

For the overwhelming majority of paraplegics, being in paid employment, or the thought of having a job, allowed them to constitute themselves as 'normal' members of society. Indeed, for most it was 'normal' to be employed as they had never known not to be employed.

Paid employment was crucial to those men who shared the responsibility of being family breadwinners. Not only was it necessary for the economic survival of the family but it was also important in the maintenance of the man's role and sense of identity. Paid employment also relieved boredom as well as generating feelings of independence, social contribution, social integration, pride, and self-respect. Pride was derived not only from doing something useful competently but also from the way other people considered it a real achievement to be disabled and to have a job. Self-respect was secured from the way being employed, 'makes you feel human', 'not a cripple', 'good about yourself' as well as not being characterized as a 'dole bludger'.

For a number of paras, the most important thing about being in paid employment was that it meant that they were no longer beholden to the state for income maintenance. Thus, removed them from the gaze of the state they were given them more control over their lives.

The overriding concern of all paraplegics is to be as independent as possible. Striving for independence extends into the economic and ideological spheres. The most effective way for paraplegics to counter stereotyping, while at the same time achieving economic independence, is to be, and to be seen to be, employed in productive work. Employment is, thus, perceived by paraplegics to be socially integrating, a means to reducing dependency, and a declaration of, and demand for, equality. In short, employment is proof of 'normality'. However, those living in areas of high unemployment, qualified this by adding 'I'm just one of 130,000'. It was 'normal' to be unemployed in this region, but this was still cold comfort to people who firmly believed they would still have a job, or find it easier to get one, if it were not for their paraplegia.

While holding down a job is socially valued, a job can also provide the setting in which one develops and grows as an individual. To conclude this section, a para articulates this aspect of his work which has been central to the process of reconstituting self:

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... the experience and the confidence and self esteem that I've got back [from having a job]...a job gives you status ...being able to socialize with people. Meeting new friends...being able to develop skills in new areas. (m,27,7)

SUMMARY AND CONCLUSIONS

In this chapter the three economic moments of paraplegia - compensation, income, employment - have been examined. Institutionalized compensation and income maintenance is provided through the Accident Compensation Commission. The ACC is the site where the paralysed subject first ceases to be a private citizen and becomes a public body. Here the subject's body is further processed, measured, codified by an administrative organ of the state. In the process the subject is normalized as a particular type of body: a paraplegic body which, in fitting certain medico-bureaucratic criteria, qualifies for compensation and a variety of services provided by the state for such bodies.

Most paras believed that the compensation they then received bore little relevance to the ongoing physical, psychological, social, and financial losses incurred by their paraplegia. Moreover, the normalizing judgements made by the petty bureaucrats within the ACC were a constant source of irritation and frustration for many paraplegics.

Over three-quarters of the paraplegics in the study had experienced a significant drop in income with the consequent decline in standards of living inducing negative feelings about self and their lot. As a result of having become dependent upon the state for their income many felt personally and socially demeaned. They would prefer meaningful, paid employment.

However, as paraplegics only about a third in the study had been successful in finding employment. Employment engendered feelings of normalcy, social integration, and independence for this group of paraplegics. Similarly, the denial of employment had important implications for self perception. Most had applied for jobs but found themselves turned down for a variety of specious reasons. The devaluation following the loss of physiological function was now compounded by enforced idleness. The immediate effect was to inscribe passivity on the paraplegic body; it was now deemed worthless in the productive process and henceforth rendered dependent. These subjects felt devalued because in the
eyes of society their bodies were interpreted as inferior and deemed incapable of engaging in productive physical activity.

For paraplegic body-subjects, self is created out of a reading of the various social interpretations of their bodies in combination with the lived knowledge of that body and the self, or subjectivity, forged prior paralysis. This process is the subject matter of the next chapter.
Chapter IX
CONSTITUTING SELF:
THE PARAPLEGIC BODY-SUBJECT AS EXPERIENCE
AND CULTURAL EFFECT

In Chapter II a brief history of the body as text revealing the inner self was outlined. This was followed by an examination of the ways in which the anomalous body had been read throughout history as a portent, an object of medico-scientific investigation, or, in the guise of 'Miracles of Nature' and 'Freaks', as sources of entertainment. The specific reading of the anomalous body that occurred in Aotearoa/New Zealand throughout much of this century was outlined in Chapter IV. As the antithesis of the iconic Truby King baby, the anomalous body was cast as physically and morally subversive to social order. As such, anomalous bodies were made subject to professional regulation in (mainly) segregated spaces throughout the country and recreated as the disabled. This is the background to the cultural knowledge held socially about the anomalous body in Aotearoa/New Zealand; a stock of knowledge that becomes frighteningly real and immediate to the person suddenly paralysed.

The question remains as to how, in light of cultural knowledge and the paralysed body, does this person constitute self as a subject? Up to this point in time this person has lived, perceived self, and has been perceived as corporeally normal: a normal, non-disabled member of society. How will this person identify, that is, constitute self as subject now? Thus far, the spatiality, changed nature, the medical and health implications of living a paraplegic body, and the social interpretations accorded that body have already been examined. This Chapter looks specifically at the processes whereby a paraplegic constitutes self as a subject. These processes involve the ways paraplegics (are able to) deploy their bodies, their readings of societal perceptions of paraplegia and paraplegics, and how these readings, in conjunction with the phenomenology of their bodies, shape identity and themselves as subjects.

This Chapter is structured around the fact that humans are both biological and social beings and the theses that first, consciousness and subjectivity are shaped by material/bodily activity (see pp.26-7), and second, that individuals constitute themselves as subjects insofar as they see themselves mirrored in the ways in which their actions affect others and how others respond to their actions (see p.118). This means that what one does is interpreted within a
cultural context which prescribes the appropriate deployment of bodies within definite structures of social relations. It is, thus, fitting to begin this chapter with an examination of how relations among people and groups are structured in Aotearoa/New Zealand with a discussion of sex, gender, and the gendered culture.

SEX, GENDER, AND THE GENDERED CULTURE: CONSTRUCTING MASCULINITY AND FEMININITY IN AOTEAROA/NEW ZEALAND

Sex and gender

In the vast majority of cases human individuals are born as members of either the 'male' or 'female' sex depending upon their physiology and reproductive capabilities. Sex is biologically determined and directly observable from the nature of an individual's sex organs. Gender, on the other hand, refers to:

qualities, traits, and activities collectively deemed to be masculine or feminine in any particular society.... [Moreover] societies socialize their members into gender roles and expectations and they associate various traits and qualities with gender categories. (James and Saville-Smith, 1994:10)

Gender is, thus, quite distinct from sex. It is a categorization based on social not physiological attributes. One is born male or female but becomes masculine or feminine, a girl or a boy, man or woman, lady or gentleman, father or mother, protector or carer, and so on as the sexed body is socialized into an age and/or status appropriate gender role. That these roles, expectations, and associated behaviours vary over time and from one society to the next, reveals the real but often concealed distinction between sex and gender. This is particularly true of New Zealand society where gender roles are naturalized according to James and Saville-Smith, to mask the inequalities engendered by the ascribed biological superiority of men over women (ibid.:11).

Gendered culture

James and Saville-Smith develop the concept of a gendered culture to show how in some societies social structure is articulated through gender relations, through the concepts of masculinity and femininity. They explain that within a gendered culture, 'there exists distinct male and female cultures which, although integral to each other, are rigidly bounded....relations between men and women are highly ritualized ....' (ibid.), with a general set of expectations attached to each sex role. In New Zealand these sex role expectations
and the contemporary practice of masculinity and femininity are still largely structured by precepts established in the 1890s through the 'Cult of Domesticity', and the motifs of the 'Dependent Woman', the 'Moral Redemptress', the 'Man Alone' and the 'Family Man' (ibid.: 55).

Under the Cult of Domesticity women's lives were structured as dependent and privatized as housewives with particular expertise in 'home-making' (cf Plunket and mothercraft pp.103-7). In turn, the scientization of housework encouraged the development of a female sphere in the labour market and the feminization of such occupations as teaching, secretarial work, nursing, domestic science, and other caring professions followed. By the 1860s, a surplus of men among the white settlers produced the rootless 'Man Alone' and a turbulent masculine subculture, both of which were perceived as a threat to social order. According to Phillips (1987), the colonial state tried to impose control, partly by promoting agricultural settlements based on the family farm. This tied masculinity into marriage and a more orderly way of life: the new Family Man had been created, a masculinity which situated men as actors in the public sphere where they were the providers for, and protectors of women; a masculinity which preserved and celebrated the qualities associated with the Man Alone but subordinated them to the virtues of the family man; a masculinity marked out by the qualities of ambition, competition, paid work, dependability, hard work, and self-reliance. Simultaneously, femininity was constructed around the motifs Dependent Woman and Moral Redemptress. As the latter, women were deemed morally superior and more chaste than men and were expected to curb man's immoral and anarchic tendencies, especially those of the Man Alone. Under these conditions, sex for women was promoted not so much as something to be enjoyed, but for the purpose of procreation, of building a stronger, healthier nation and empire (James and Saville-Smith, 1994:32-55).

While the Family Man contrasted with the independent, disorderly, unattached Man Alone, his sense of pioneering self-sufficiency continued in the family home within a gendered division of labour. Here the natural role of the Family Man is considered as the primary income earner, the 'family breadwinner, and that he generally confine himself to 'manly' work about the house: that is, routine maintenance such as roofing, fencing, repairing appliances, fixing the car, etc and, perhaps, taking the children to sport on the weekend. However,

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1 While I have some reservations about the bluntness of James and Saville-Smith’s argument, they provide a useful framework for the points I wish to make about the lives of the people I am discussing in this chapter.
because the idea of domesticity did/doe not appeal to all men, the Family Man is integrated with the attractive features of the Man Alone on the sports field (especially rugby), in the pubs, and service clubs. Here contemporary masculinity is created, celebrated, and reaffirmed in ritualized forms of male behaviour which assert sexual/physical power, self-control, and control over others (ibid.:36-42, 48-52).

The natural role of the Family Man contrasts sharply with that of his female counterpart. She is constructed as a housewife and made overwhelmingly responsible for the cooking, cleaning, bearing, rearing, mothering, and meeting the emotional needs of a particular man and (his) children. Notwithstanding the effects of the women’s liberation movement, beginning in the late 1960s, and the oral contraceptive, contemporary female culture and femininity is still largely structured around the Dependent Woman motif, in self-sacrifice, in meeting others’ needs - especially men’s, and in economic dependency (ibid.:54-61).2

In this section the distinctions between sex and gender and the notion of a gendered culture have been examined in order to contextualize the process whereby males and females become men and women in Aotearoa/New Zealand. This is particularly important in understanding the constraints which male and female paraplegics face as they reconsider their selves in light of their paralysed bodies and (re)constitute themselves as masculine and feminine subjects. It is apposite to conclude this section with a quote from Connell, who defines gender as:

... a historical process involving the body, not a fixed set of biological determinates. Gender is social practice that constantly refers to bodies and what bodies do, it is not social practice reduced to the body. (Connell, 1995:71)

SELF AND THE DEPLOYMENT OF BODY

This section is divided into two parts, the deployment of the body intimately in private space and its general deployment in public space. Part 1 focuses on the physiological effects of paraplegia on sexual function and the reproductive capabilities of paraplegics and how these effects structure the ways in which male and female paraplegics constitute themselves as

2 For a fuller account of the creation of a gendered culture in colonial New Zealand and the contemporary practices of masculinity and femininity see Bunkle and Hughes, 1980; Brookes et al., 1983; Gray, 1983; Kedgley, 1985; Cox, 1987; Phillips, 1987; Coney, 1993; James and Saville-Smith, 1994:32-62.
masculine or feminine subjects. Part 2 is concerned with how paraplegia limits the ways in which paraplegics are able to deploy their bodies generally, and how this limits and shapes the subject positions they have open to them. Underpinning Parts 1 and 2, although more so Part 2, is a materialist analysis of self that draws upon the ideas of Marx's notion that consciousness is shaped by purposive labour (see pp.25-7). This notion is adapted to focus on the ways in which paraplegia determines what paraplegics are able to do with their bodies and how this shapes consciousness and subjectivity in particular ways. In this sense, it is, perhaps, more accurate to describe this section as a corporeal analysis of self.

PART 1:
THE PRIVATE AND INTIMATE DEPLOYMENT OF THE PARAPLEGIC BODY: THE PHYSIOLOGY OF SEX, SEXUAL FUNCTION, AND THE GENDERED SELF

A central feature of the masculinity created around the Family Man and Man Alone motifs is that of sexual mastery and sexual potency. This complements the femininity created through the Cult of Domesticity which accentuates women's alleged nurturant and maternal capacities. As a consequence, it seems quite natural, or biologically determined that a man or woman eventually settles down (he, after sowing his 'wild oats', she, perhaps after some sexual experiences of a more judicious nature), gets married, and raises a family. But paralysis disrupts the gendered roles of Man Alone, wife/husband, mother/father and the associated expectations, particularly in the areas of sexual function and procreation.

Physiological (sex-connected) determinates

Paraplegia radically transforms the deployment of the body in terms of sexual activity. At a physiological level there are both marked distinctions and marked similarities in the ways in which male and female bodies, as sexual and reproductive bodies, are affected by paraplegia. Male paras, with lesions to the thoracic area, can experience erections on a reflexogenic basis (that is, not on a voluntary basis and not emotionally related to a sexual situation) while those with breaks in the lumbar and sacral areas do not. Ejaculations may not occur and fertility is usually impaired, so male paras lose the ability to procreate. With

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3 This assumes heterosexual orientation. In this study, since only one person identified as homosexual, all reference to sexual activity can be assumed to be of a heterosexual orientation.

4 Men with spinal cord injury tend to have testicular atrophy, and, for causes unknown, generally low sperm counts, low sperm motility and mobility, and an abnormally high incidence of sperm malformation. (Sommers 1992, pp.275-98, Ozer and Phillips 1987, pp.147-60).

(continued...)
female paraplegics, menstrual periods tend to resume within several months of injury. Fertility is unimpaired and there is no physiological reason for female paraplegics not to conceive, bear, and rear children if they so chose. As paralysed bodies, both male and female paraplegics share a physiology marked by the inability to move freely and spontaneously, the absence of tactile sensation below the level of their breaks, the inability to reach and experience genital orgasm, and bladder and bowel incontinence. As a consequence, both male and female paraplegics may experience their bodies as less libidinal and may be perceived as bodies which are less desirable sexually.

**Patterns of response**

In the interview situation, women were far more likely to defer from discussing sex and sexuality with me than were men. This pattern was repeated in the survey. A number of explanations can be advanced for this gendered response. First, as a man and, hence, an outsider, I may have been perceived as lacking the knowledge to really understand women's sexuality, the emotional processes, and so on; the reverse holds for male respondents (this applies especially to the interview situation). Second, again as an outsider, I probably did not know the right questions to ask women. Third, the sequencing of questions in the survey prioritized physiological aspects and were directed exclusively towards males; women may have abandoned the section at this point. Fourth, the structuring of femininity around the Moral Redemptress motif encourages women to be discreet in discussing matters of sex, especially with men. In male culture, sex is treated far more instrumentally and openly talked about with sexual prowess being cast as the essential quality of what it is to be a man. From these perspectives, the absences and losses which were verbalized so forthrightly by men can also apply to women: it is a matter of listening just as closely to what was not said as to what was said.

That more material will be presented in this section from a male perspective is partly explained by the above patterns of response and partly by the demographics of paraplegia. Young people are paralysed at a ratio of four males to every female. In this study, male participants outnumbered females at a ratio of three to one. Compounding the imbalance of material was the fact that male sex/reproductive capabilities are more dramatically affected...

([...continued])

5 At the time of this study the application of the new reproductive technologies to paraplegia had hardly begun. Significant advances have since been made and the possibilities for a male paraplegic to sire his own children are now greatly increased. The associated costs may, however, preclude many as the procedure is not available through public health and ACC does not cover the $7000 fee.
by paraplegia at a physiological level and, hence, males had more to talk about, especially the subjective and social sequelae. Notwithstanding this imbalance, the reflections of both male and female paraplegics will be presented together (when and where appropriate) to show the continuities and discontinuities between their experiences. Equally important is the wish not to subordinate one set of experiences on the basis of sex to the other. The reflections have been organized into the themes of sexual function and identity, fertility, desire and desirability, contingency, and strategies for coping.

**Sexual function and identity**

In terms of identity, sexual function appeared to be far more crucial to the males in this study than it was for the females. For a young male, at the height of his sexual prowess, the awful discovery that he can no longer achieve an erection at will deals his masculinity and self-identity as a man a serious blow:

...It really terrified me ...I don't get an erection....that really blew me away. Being a typical macho ...that was sort of it. This is the end. It stops at my dick ...because that is the basis to my relationships before my accident....  (m,19,8)

Such were the feelings of inadequacy and abnormality, one young man had resorted to surgery and a penile implant: 'I had an operation ...I wanted to get a "normal" sexual relationship going' (m,21,10). Another, who was crushed by his total inability to get an erection (penetrative sex was crucial to his sense of manhood), revealed:

I'm thinking hard about this implant thing....it will just be good to see it there. It will make me feel (pause) like I can't relate to men [because] I feel less than a man.  (m,29,1)

The loss of the power of erection clearly signifies a terrifying and disempowering break with the past, with being here and now as a man. In terms of self-identity, some paras felt that their 'manliness' had been destroyed and that they were now only 'half a man':

... you can't fulfil a man's role ...so you are damn near worthless.  (m,32,2)

Being paralysed doesn't bother me. It's the manhood that's taken away from me....That's one part of my life that I would love to have back.  (m,29,1)

However, it was not just a question of an erection. A deeper issue was that of natural fatherhood, of man the progenitor.
Fertility

The question of fertility raised different issues for female paraplegics than it did for male paras. For women, the matter of controlling fertility remains, while, for men, the issue is infertility. When in relationship or considering marriage or the possibility of starting a family, the full implications of infertility are realized. Identity is again thrown into sharp relief against notions of manhood and the motif of the Family Man - man the progenitor, man the protector and provider. Many expressed a profound and deep regret over their inability to beget their own children:

... the hardest thing would be the acceptance that you can't even breed....breeding is a human urge....That will be my one fulfilment: that I...have my own kids. I feel like you do it all for nothing ...I've achieved and got material wealth....I've got life all sussed out. [But] I'm doing it all for myself. Which is a bit of a drag. (m,19,12)

It is evident that patriarchal lineage, the reason for being, is also an important consideration. Perhaps the para who blurted out, 'Every man wants a son,' was closer to the truth than I realized at the time.

Loss of sexual function and infertility were perceived by some as adequate grounds for rejection:

I didn't see why any female would want to go out with me ...not being able to have kids .....We could adopt kids but then they are not a part of either of us....I feel that every female has the right to experience having a kid and I feel that I am taking that away .... (m,21,2)

While there may well be an element of self-pity in the above quote, it does capture the tendency of some paras to not look beyond their body as a reason for failure in relationships. Another was not dismissing all chances of relationship, just gauging the odds: '...my chances of ever having children are slim. This may well affect attitudes of a future partner' (m,24,10mths).

In some cases identity was tied to fertility:

Impotent. Useless. Failure. Men feel like sexual bombs. If there's no explosion you're useless. (m,29,8)
This quote is replete with abstract symbols of masculinity - sexual power, vigour, potency. For many of the males in this study, the fact was that their bodies lacked that maleness, that ultimately they could only constitute themselves in terms of lacking that sexual power and energy: as males but not men.

Compounding the pain of the more or less permanently flaccid penis, infertility, and deflated egos are losses which apply equally to female and male paraplegic bodies. Since the 1960s, second wave feminism and oral contraceptives, women have expected the right to sexual activity devoted solely to receiving and giving pleasure. Hence, with paralysis the pleasure content within the sex lives of both male and female paraplegics may be diminished by the loss of sensation, the loss of sexual and genital pleasure, the loss of orgasm, a loss of libido, incontinence, and general feelings of sexual unattractiveness.

_Sensation_

When we lose the unthinkable, something that is taken for granted and never fully appreciated until it is gone, then the good things about it seem to grow in stature and become all the more important and desirable. The loss of tactile sensation is one such thing, especially feeling in the genitalia. For paraplegics, the loss of feeling means that sex and how they experience self as a sexual being, is changed irredeemably, that sex and self are somehow incomplete, that there will never be another orgasm, or if there is, it will never be experienced as intensely as it once was:

... But this sex thing was always throbbing away at the back of my head....Its not so much about not having kids ...I can’t feel the touch ...I can’t feel myself inside....And it just makes me go nuts.... (m,29,1)

... the fact that I can’t orgasm ...is extremely frustrating....the one thing that fucks me off ...is not coming ...if ...a fairy godmother turned up and said, "you can either come, get an erection or walk," I would really think about it. (m,19,8)

I would like to feel the sensation of making love to my wife. Losing such a vital part of your life causes anger, frustration, and despair.... (m,23,7)

But ...I wish I could feel, you know? Wish I could feel it....Like when you get down to it ...you can just look and imagine and think about it.... (m,15,10)

I feel it, I’ve still got all the urges. It’s still there you know. I’m just a human male. I think about it about fifty to seventy-five percent of the fucking time don’t we? I’m sure I do anyway. Any spare moment - a catch of leg or, you name it, you’re at it. (m,19,8)
Clearly, the male paraplegic body, replete with sexual memory, is, at times, a pained body. It is always a lacking body and frequently a desiring body. And while it is the male paras who are doing all the talking about sensation and orgasm, surely the same losses apply to the female paraplegic body as well?

**Libido and desire**

In spite of the gendering of the female body, the pleasures of the flesh are not restricted to men. This was obvious in what some women said when they talked about the loss of libido they had experienced following their accidents. More revealing, was the way in which they spoke about it: their words were underlaid with a deep sense of loss and regret:

> I've lost all that [sexual desire/activity]....I think both my husband and I [regret this]....I think it's a big strain on both partners really. No, it's something that ...would be one of the biggest things really that you've got to come to face. (f,49,8.5)

While loss and regret was deeply personal, it was experienced within the context of marriage relationship. As wives, the sex lives of these women were structured around meeting the sexual needs of their husbands. Their loss of libido not only affected the way they constituted their femininity and themselves as women, but also as wives:

> I don't... get the urge to partake of that sort of thing. I forget about it quite often which isn't that good being married. (f,23,2)

The feelings of guilt engendered by this dereliction of wifely duty were sometimes rationalized by firstly, constructing their paralysed body as sexually undesirable and then evaluating their husband's perceptions and desires in terms of that construction:

> After my accident ...I just wasn't interested. And, another thing in my mind is the thought that ....most probably for him it wouldn't be the same....I think it [incontinence] probably has got a lot to do with it too. (f,44,8)

Two males reported a total loss of libido. One's body was racked by root pain and the other, who had been paralysed for less than a year, said he had more urgent things to think about. He was more concerned with establishing a reliable bowel regime, settling into living at home, and finding employment. Both men were in long term relationships.

It would be doing a disservice to those men and women involved in this study not to report that many reported no loss of libido or desire and indicated completely satisfactory sex lives
Sexual activity was, however, affected by the way paras perceived their bodies in terms of sexual desirability.

**Desirability**

Many paraplegics are desired and desiring lovers. However, bladder and bowel incontinence is just one of a constellation of factors which made some feel less attractive sexually. One man put it this way:

...the tricky point [is]...you've got to find [women] that can handle uritips and bags and night bags. And pissing yourself. And the odd shitting yourself. And, you know, all the things that happen. (m,19,8)

Those comments apply equally to women: they have the same body problems to consider as lovers and when choosing a sexual partner. One woman, who was open to a relationship, reflected on her body as the transgression of all conventional standards of beauty and desirability:

... it's not as appealing ...everything's just paralysed and it's all just hanging there. And you look in the mirror and there's this body sittin' there and paralysed boobs... and you think "Christ! Is this me? Imagine anyone else looking at that and finding it appealing."...it just makes me feel like that sort of thing is not really possible, or that you could be very desirable anyway. (f,23,4)

A man, speaking on the same topic:

I feel less attractive to women and less of a sexual being....I don't try to find a partner because I feel it would be unlikely they'd be interested in me. (m,24,7)

Both male and female paraplegics were fully aware that sex was an important part of a relationship and that sexual performance was central to having a fulfilling sex life. From this perspective, their paralysis made relationships fraught in terms of performing as sexual women and men, of fulfilling their gendered expectations in the bedroom.

**Contingency**

Sex can never be the same again; it is marked by contingency: '...three years after my accident ...I got back into sex but it was always very awkward and I never felt confident or relaxed ....' (m,19,8). For both male and female paras, feelings of contingency, failure, and

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6 A quadriplegic friend of mine once remarked how much more womanly and attractive she felt since taking up intermittent catheterization to control bladder incontinence, as she could now wear knickers. Technology had freed her from her nappies.
inadequacy are generated partly by their paralysed bodies and partly by social context. They live in a society in which sex manuals, lifestyle, 'girlie', and women's magazines proliferate with articles on sexual technique. Techniques which, in stressing bodily movement and flexibility as the prerequisites for achieving orgasm and sexual fulfilment for both self and partner, create particular expectations. Movement and performance were mentioned by some paraplegics as introducing contingency into their relationships.

One woman (35,1.5), reflected, somewhat wistfully, on how since her accident sex had not really been the same; she could not be as physically active in love making now as she had been previously. Things such as her, 'legs falling out of bed' introduced a clumsiness that detracted from the overall effect. She indicated that this was a source of considerable loss within her marriage and, hence, in the way she constituted self. Duty, movement, and fulfilment were also at the heart of comments made by two men:

For the wife to lose her conjugal relations places stress not only on her but also on the husband who thus feels a failure and inadequate. (m,53,1.5)

Sexual fulfilment is important to women and it is important to me to be able to complete my designated sexual role... I am often forced to take a more passive role - I feel I am less sexually attractive. (m,20,6)

For many of the male paraplegics, their sexual dysfunction not only produced a sense of contingency in terms of confidence in the ability to enter and maintain a relationship but also in terms of their masculinity and manhood. Both moments of contingency stemmed from their inability to achieve an erection. Male culture teaches them that an erect penis is indispensable to sex, proper sex, that is. While many were able to dismiss this proposition intellectually, it was difficult for them to do so emotionally - even when told so by their lovers, their women friends, or by professionals. The dilemma of who to believe on this topic was captured by a para, who, while asserting that he did not see sexuality purely in terms of an erection, added:

...I've spoke[n] to women that I've had really close ...relationships with and even if they say ...that you don't need to have an erection, and that I don't need penetration and all this. Lies. They even told me that they do. They do like it. And it is an important part of the relationship. So all these books and all the crap that they tell you that it's all right you can still have sex. And you don't need to have an erection and all that is, you know, a load of crap ... a woman likes a good dorking! (m,19,8)
Two opposing issues are at stake here. First, the central tenet of male culture which simultaneously preserves masculine sexual imagery and constructs a femininity purely in terms which serve men's sexual needs (note the ending phrase). Second, a femininity which serves the sexual needs of women without upholding oppressive masculine ideals, and which, in the process, constructs a masculinity based on tenderness rather than on raw, instrumental power. For a male paraplegic to totally subscribe to the latter, it might seem as a bit of a cop-out: not only does it undermine staunch masculinity, but it says, in effect, that women will make allowances for the male paraplegic, the incomplete man. Moreover, it places him in a dependent position within the relationship; it makes him vulnerable. Emotionally, he can never really accept or believe the message. To him, a man, penetrative sex is authentic sex, the expression of masculine, sexual self. On this, another para added:

If I was a woman and I was going out with a guy that was no good at sex ....I have talked to [my girlfriend] about it and she said that it doesn't make any difference. But to me, it always will (m,15,2)

Sex without an erection may not be so important for the woman involved, but for the man, penetration is the defining moment.

Redeploying sexual energy and male power

Bob Connell (1995:55), cites a study carried out in the United States on men who could not sustain gender performance as a result of physical disability. One way of coping was for men to reformulate the definition of masculinity, bringing it closer to what is now possible, though still pursuing masculine themes such as independence and control. Where this leaves women paraplegics, in terms of gender redefinition, who just as resolutely pursue independence and control over their own lives (the women in this study most certainly did), is open to question. However, one para did link the effects of the urge for independence with relationship:

I've lived alone so long now that I'm viciously independent. Paraplegics tend to find it harder to get relationships together....Because they ...need to be independent. You know, you do everything yourself if you're a para....it's a drag really. (m,19,8)

Any number of male or female paras could have made this statement: the ethos of independence, an overwhelming, almost irrational, desire for physical independence pervades

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the paraplegic subject. On a number of occasions I was struck by how this ethos - the fear of, or to be seen to be, becoming dependent - precluded some paras, especially males, from developing relationships: emotional isolation becomes the corollary of physical independence.

As has already been mentioned, a number of the paras indicated that they had successfully learned how to redeploy their bodies in private and intimate space and were leading quite satisfactory sex lives. That men, again, spoke most openly about their sex lives, courting, and so on since their accidents is probably due to the fact that most of the women were married at the time of their accidents and remained so. Not all male paras were overly pessimistic about their impaired sexual function. Indeed, some saw it in a positive light and redeployed their sexual energy quite productively within sexual relationships. Even though the males in this group were mostly able to get erections, gratuitous sex was out. Their changed circumstances had forced them to become more holistic in their relationships, to develop their emotional sides and to concentrate more on giving pleasure than receiving it. The outcome, the reconstituted self, was a far more likeable fellow. One man, in the armed services at the time of his accident, explains:

... I'm less self-centred. And I'm not as egotistical as I used to be. [...] [before] You couldn't wait to get into bed with a woman. You were always talking about laying women or whatever. But these times, now it's being able to take a woman out for tea ...or whatever. Those sort of niceties. So the relationship becomes a bit more meaningful. (m,27,7)

With loss of feeling and uncertainty of erection, this para's approach to women has become less instrumental. He had discovered that there is pleasure of a different kind within the ritual of courting. Hence, the meaning of relationship had expanded and with it a redefinition of masculinity and the terms on which he constituted self as a man. Similar views had been expressed by others:

Initially it can be difficult. However it doesn't usually prove that major a problem... because sexual intercourse is only a small part of sex/loving. (m,20,6)

The most common expressed mode of redeployment was to focus on giving sexual pleasure rather than receiving:

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8 In a later interview, a woman commented, '...I do think some paras put up a wall and don't let people get close....there's a fine line between independence and bloody-mindedness' (f,26,10).
... emphasis is changed to ... meet wife's needs. Satisfaction is derived from this. (m,53,1.5)

... I wish to satisfy them more than me as before. Because, if I can't, then I feel something is missing. (m,21,10)

This transformation of the male role can be read in a number of ways. Firstly, the giving of pleasure to the one you love can be seen purely in terms of love-making, of expressing love differently. Also, much physical and psychological pleasure is personally derived from this act. Or, it might be read as a form of compensation, a making up for that lost manhood, a means of legitimation. Or, more darkly, the giving of pleasure can be read as the maintenance of male sexual power. For some, the control element was barely below the surface. It seemed more of a doing to than a freely giving of; it was almost penetrative. Probably, for any particular subject no single or the same reading dominates on all occasions. Just as a variety of methods are likely to be deployed, it is most likely that a complex combination of reasons obtain for/during the act of giving pleasure.

Many paraplegics, both male and female, had, however, managed to redeploy their sexual desire and drive in a very productive way within the context of relationship. By way of closing this discussion on a positive note, two such men are quoted. The first, in defining himself as an active sexual person, wrote, 'I enjoy the closeness of sex to [sic] much to give it up' (m,21,10). The second, reflecting on how he would like to see the topic of sexuality dealt with in the Spinal Unit, observed, '...you can only convince them [patients] so much. Its not until they try it, that they will realize how much fun it still can be' (m,23,4). This may well be so, but, sometimes, the potential needs to pointed out. While both male and female paraplegics shared a corporeality which, for some, operated to disqualify their perception of self as an active sexual being, many were inhibited by a lack of knowledge about the possibilities for having a creative and productive sex life.

Lacking knowledge: working or not-working in the dark

The most disturbing fact to emerge from the discussion on sexuality was the overall level of ignorance. This was not surprising given the very low priority afforded counselling at the Otara Spinal Unit in its body-centred, rehabilitation programme. As a consequence, many paras were figuratively and literally operating in the dark when it came to the expression of their sexual self. Infertility, and the inability for males to father their own children, was accepted fatalistically as a natural part of paraplegia for males. Married paras complained
about the lack of proper counselling and information on technique, fertility, transmission of UTI, and so on.

Only just over a quarter of respondents said that the opportunity to discuss sexuality was available to them at the Spinal Unit. While some individuals were 'helped accordingly' when they sought information on their own initiative, others complained about the haphazard way in which assistance was made available. One respondent wrote, 'A pathetic joke, but almost hidden reality. I frankly wonder if they really know anyway' (m,27,9). Another wrote, 'They gave me a 20 minute 'blue movie' to watch on my own and that was it. No discussion!!!' (m,50,4.5).

This lack of information about the potentiality of, and the possibilities for, deploying the paraplegic body as a sensuous, sexual body had important consequences for the ways in which paras (re)constituted self. But this was not just confined to the area of sex. How and what paras did with their bodies generally was fundamental to the formation of self.

**PART 2:**

**SELF AND THE DEPLOYMENT OF THE PARAPLEGIC BODY IN PUBLIC SPACE**

Marx's thesis that purposive labour shapes human consciousness and subjectivity, serves to focus how paralysis delimits what paraplegics are able to do with their bodies and how this shapes them as subjects in particular ways.

**Doing and being**

Earlier the effects of physiological function on subjectivity and the constitution of self as a subject were examined in the contexts of employment and changed leisure activities. I also asked paras to evaluate the extent to which they believed their paraplegia impacted on their ability to do work by ranking it in terms of effect (Table 7.0:294). Many qualified their answer by saying that it very much depended upon the type of work involved. Paralysis meant that much of what they had formerly done with ease was now beyond their ability. How they now deployed their bodies was very much determined by their paraplegia: paraplegic labour power was only applied to tasks which could be completed with 'only a little' difficulty or 'none at all'. The corollary is that whole categories of work, doing, and play were now denied, excluded from the paraplegic body-subject's reality. It follows that if consciousness is largely a product
of both what one does and how one does it, then there must be a paraplegic consciousness, a paraplegic subjectivity, that is as much shaped by what paraplegics can no longer do as by what they can do.

In terms of not being able to do things, it was the inability to carry out the mundane that provoked real changes in the subject. Paralysis means that many of the day-to-day, taken-for-granted ways in which one used to deploy one's body no longer obtain. The corollary pertains and the pleasures and securities inherent in a particular role from which identity and worth are derived are now gone and, with this, a part of the regular 'day-to-day' self:

I couldn't do the things that I used to do before....[this] didn't feel right to me....Like cleaning windows, things like that....I felt different in many ways....I was very active....I did a lot of gardening ...mowing the lawns ...shearing our sheep. All those things I miss.... (f,44,8)

A part of self is lost forever, and still missed, as self is constituted in terms of lack, of what one used to do and can now not do. Often, feeling 'different' about self can translate into a sense of worthlessness and superfluity:

... I couldn't do anything out on the farm....All I could do still was just keep the house....It was probably tied up with the frustration and trying to come to grips with the fact that you couldn't do these things any more but you felt useless....You really feel at that point in time that your life's coming to an end. You know that you're not going to be any good to anybody for anything. (f,33,11)

But this woman was to find that time was a great healer. She looked for ways in which she could be useful, another raison d'etre. She continues:

... It didn't really last that long ....I thought "well this is no good...Get on with it ...it's not going to change so you might as well make the best of it."...there are still times I feel that way. I don't think you ever get past that but I found that as time went on ...I could ...cook ...sew ...do the washing whatever....I could still look after my family.

**Becoming a housewife: a choice of last resort?**

Clearly, the prime activities associated with the 'true' woman, as prescribed within the Cult of Domesticity, can still be performed as a paraplegic. Homemaker is, thus, a ready made subject position this paraplegic can re-orientate herself to. This is not to say that substitutes are always as satisfying, as something one would readily want to be identified with, or would freely tie identity to:
... Given half a chance I'd be out on the farm. Not in doing the housework ... I hated housework and that. But you did what you had to do and you looked after your family.

The forced transition from farmer, wife, and mother to homemaker is not without its tensions and regrets. Since a major way in which an individual makes self into a subject is by observing how others respond to his/her actions, paraplegics tend to feel that what they do is always subject to the evaluative gaze of others, initially at least. The outcome is often an increased self-scrutiny, a self-imposed 'having-to-prove-self-as-good-as-former-self' by being more efficient and effective:

... But then you sort of felt that you had to ...make up for the fact that you couldn't do so many more things by ...trying to be better [at] what you could do....But I still loathe and detest it [housework]. (f,33,11)

In this instance, paraplegia had forced this woman to wholly adopt a normative, gendered, subject position which she considered vastly inferior to her former nonparalysed self. Inherent is a reduction of self, being, and self worth; she has become a self-monitoring, scrupulous self that is not always entirely happy with her lot.

Undermining the Family Man and Man Alone motifs
When paras were asked what the most difficult thing about paraplegia was for them to deal with, a number immediately said the little things in life they could no longer do, the things which stymied their day-to-day being. The following captures the tenor of those responses:

Being able to change a bloody light bulb. All those little frustrating things. Not being able to fix your car up like you use to and things like that. Now you have to take your car into a garage to get it done. (m,30,8)

A conversation then ensued in which we discussed this particular aspect of being paraplegic, the 'thwarted self' which obtains at that particular moment of frustration. We agreed that while someone is always willing to help out - to paint that architrave, hang that painting, unblock the spouting - they can never do it as elegantly or quite as well as I would have done it! Then there is the matter of having to ask for help, of becoming a dependent self:

Relying on other people to often help with simple things....I don't like asking others for help as I know some ....will think I'm just lazy. (m,24,10mths)

For males, asking for help is not just a question of being perceived as lazy. It runs counter to the precepts of independence, self-reliance, and self-sufficiency which are central to the
construction of their masculinity. These precepts are also equally applicable to female paraplegics, because, more broadly speaking, asking for help runs counter to the notion of a successful paraplegic who is independent and self-reliant.

Parenting
In reflecting on the hardest thing about paraplegia for him to accept, a young father wrote that he missed, 'Playing in the grass. Running with my little girl' (m,20,2.5), most of all. An important ingredient of self-as-father is denied this man by virtue of his inability to deploy his paraplegic body in play with his young daughter. Similarly, while a woman retains the biological capacity to be a mother, the way she mothers is disrupted by her paraplegia. She, too, can no longer run and play with her little child; the rearing of children and the housework associated with being a wife and mother is that much more difficult as a paraplegic (see above, p.180). Hence, the way a paraplegic constitute him or herself as a parent changes with their body's changed capacity for action.

Another theme which emerges from these reflections on parenting, was that of the lack of mobility and the associated physical geography. This, in combination with the need to consciously regulate bodily functions, means that living the paraplegic body productively is a disciplined and planned project: a certain spontaneity goes out of life.

The non-spontaneous self
All parap torn upon the fact that paraplegia had removed the spontaneity from life and, as a consequence, they, the 'I', the 'self' was less spontaneous and free. While some couched this in terms of mobility and the freedom to go where and when they pleased, others spoke more openly about how, in the quest for certainty, they had become more calculating and scheming: 'Much more calculated and deliberate - planning/moderated the excitement and spontaneity leading to deliberate personality' (m,27,9). The contexts in which this deliberation and calculation occur are elaborated in this longer quote:

... I make sure I've got my bills paid. And then I've got those chores done so as I feel that gives me a sense of security. I'm not as free a spirit as I was. I couldn't just say I'm not going to quit my job today, I'm going up North tomorrow. To do things is a bit more of an effort. I have to make sure that I've planned to get things done....I just can't sleep on the side of the road. Do things like that. So that's altered my life style. I feel that it's mellowed me a lot. I'm not as aggressive a person as I was in my dealings with other people, mainly because to get things done you have to learn how to manipulate people. Not in a horrible way, but just in your everyday dealings with them. To get things done you have to learn to get along with people .... (m,19,8)
As you can see, the change has not been totally without merit. Perhaps this person's mellowing is best explained by the reduced power of the paraplegic body and the need to negotiate rather than to do or to demand? It all gets a bit wearisome, the need to analyse and negotiate, to second guess, to present self in the most pleasing manner, to think and plan ahead. It is a continual drain, in short:

It sucks. ...you can't just say, right I'll jump in the car and go to the shops. You've got to think where will I park? Can I get into that shop? ...you've got to think of every little bit of it. How long is it going to take? How long can I afford to be away? if I'm going to be away that much longer. That sort of thing. Takes all the fun out of life....Spontaneity....Not being able to do what you want to do when you want to do it. (f,33,11)

But this does not have to be a bad thing. For some paras, the forethought, the planning and the attention to detail demanded of them if they are to lead productive lives, has positive spin-offs:

...what's also helped being in a chair is organizational skills. And planning and goal setting because you've got to plan your whole routine for weeks or days ahead....wheelchair people are also good managers because they have to manage their lives as well as everything else. (m,27,7)

In this instance the product is an efficient and effective self; a self able to cope with more than one problem at a time. Indeed, these organizational and management skills that come with living a disability are now promoted within vocational rehabilitation as attributes in high demand on the labour market (see Hunt, 1991).

In summary, the enselved paraplegic body can be said to be lacking in spontaneity precisely because the self must attend to the physical geography inherent in that body as well as plan, accommodate, coordinate, and regulate bodily functions. Hence, in part, the paraplegic body-subject is a non-spontaneous self, a self tied to routine and calculation in order to effect corporeal predictability. Because the body cannot be changed, only regulated, this can produce a certain resignation or fatalism.

**Fatalistic self**

Another element of the paraplegic subject emerged as the quiescent acceptance of a variety of traumas and/or discriminatory practices with a mere, 'that's the way it is.' This fatalistic mind set was exemplified by the paraplegic working for the data entry firm (see previous chapter). Having trained an able-bodied person to do his job if he was absent, he was
promptly sacked and replaced by her. He accepted this as 'human nature': who, after all, would employ a disabled person when they could have an able-bodied person doing the job? Others mentioned how they sometimes appeared quite hard-hearted in terms of not showing great concern or sympathy for those who might have sustained a serious non-permanent injury or experienced some misfortune. Of course, they experienced sadness about the situation, but, while offering whatever support they could, they never really went over the top in their expressions of sympathy because these setbacks were just part of life: one accepts and lives with the things one cannot change.

This fatalism can be partly explained by the fact that many of the subjects had experienced close brushes with death. In the course of getting paralysed they had lived through horrible accidents and survive today as paraplegics. Paraplegia has, in turn, forced them to live with, although never entirely accept, things about their bodies which they can never change. Things like not being able to walk, not being able to control one's bowels, not being able to feel, experience sensation in their paralysed regions. This is their lot, their karma, which they must live out. Also, there is the matter of choosing one's battles carefully, of spending one's time and energy most productively.

In contradistinction to those who 'accepted' their paraplegia and got on with living, in a few instances paraplegia did eclipse all other aspects of the subjects' lives. These individuals were in constant agony from root pain. Another was devastated by the fact that he could no longer get an erection: his sense of self was totally destroyed because he could no longer deploy his body in the sex act in the manner of a real man. Another was so consumed by anger at being paralysed, that he could also be considered a totalized subject. He wrote:

I don't think about 'myself'. I'm just plain angry that my physical disability dictates the whole way I live....it is a living hell because of it's permanence and any paraplegics who say that it is not are, I feel, bull-shitting themselves, no matter how well they have adapted. All you have to do is to ask if they would prefer to be as they were before their accident. (m,23,7)

In opposition to these totalized subjects, most paraplegics live their lives without constantly thinking about their paraplegia: they just get on and do within their corporeal limitations. There are moments, however, when these limitations hit home and with them the reality of being paraplegic. It is then that their anger and frustration is most likely to emerge. A number

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9 At the time disabled people were not covered by anti-discrimination legislation in New Zealand. The Human Rights Act 1994 rectified this situation.
candidly admitted that, despite appearances, deep down they had never accepted, nor were they ever likely to accept, their paraplegia. There is, I strongly suspect, a deep-seated anger at being paralysed - an angry self in all paraplegics.

But that deep-seated lack of acceptance does not necessarily translate into a desire for a 'cure' as asserted above. After listening to many paras speaking on this subject, qualifications need to be placed around the notion of 'cure'. Certainly, at the time of their accident, or soon thereafter, surgical intervention to repair the damage to the spinal cord would have been gratefully accepted. But now? Few were overly concerned with walking again: this would require major readjustment and rehabilitation again - a re(re)constitution of self - that might not be worth the effort. No. The overwhelming majority of the paraplegics I spoke to would be more than happy just to recover bladder and bowel continence, sensation, and sexual function. Of course, those with root pain would love that to be cured as well. Instead of longing for a cure, however, most paras just normalize the ways paraplegia structures the modes in which they deploy their bodies.

_Incorporating paraplegia: making the abnormal normal_

For most paraplegics, paraplegia, their sense of self, their lives, are not so much measured in terms of good or bad as in terms of difference, of being different. Indeed, what life or self might have been outside the paraplegic body is just idle speculation. One has to live in the present, live the paraplegic body from one moment to the next. What this involves is the organizing of one's life around one's paraplegia to ameliorate its consequences. As a person looks at old problems with new eyes, develops new strategies, new ways of deploying the body, s/he becomes, in many ways, a new person, a new subject without necessarily abandoning her non-paralysed self. Rather, that self is developed, extended as paraplegia is incorporated into being. A woman explains:

> [Paraplegia] means that I'm different....Physically that I'm different. The disability is so obvious. It does mean that some things in my life I find more difficult to do than the average person. But, apart from health, at home and in my family situation it makes no difference. It's not an issue in our lives....We incorporate it into our lives....You automatically think about [it] when you go camping. We take our own Porta loo because I know I'm not going to be able to get into the loo there. But it's just an incorporation, it's nothing that's an issue ...it doesn't make me feel any different about [my husband] or [he] feel any different about me. That's the thing. It's a head thing in a relationship I think. (f,26,10)
While this para accepts her physical limitations as her normal state of being, for others they were a cruel reminder of their status as paraplegics. A long quote follows in which the process and aims of incorporation are clearly articulated. In the quote references are made to dream sequences and the dilemma of having to inform others of one's corporeal limitations without placing self in a position of inferiority. Similar comments were made by other paraplegics:

... in the past there wouldn't have been a day gone by that I wouldn't think,"what a bastard this is. I wish I could get up and have a game of rugby" or something like that. So I used to dream that I could still walk, but I no longer dream that I can walk. In the dreams I'm in a wheelchair....so I guess I've got to the stage where I've accepted it. And it's only when something comes up that you think, "right I would have liked to have been asked out there," but I know I wasn't asked out because I'm in a wheelchair and it's too difficult to go there or whatever. Then it really comes up and bugs you....I've got into a life-style that is adapted to it I guess. Because I've adapted to it I don't really think about it. I just get in that groove sort of thing....I'm trying to be a normal human being. I'm trying to be as regular as you guys and then I ...suddenly think, "Christ! I'm paralysed. You've got to make allowances for me." So it works both ways sort of thing, you know. It works both ways. I try to be as normal as possible. And at other times I think ..."you've got to make allowances". (m,18,14)

Perhaps, the quandary for this para is in trying to be a 'normal human being' in terms of non-paralysed people? Paras who lived life on their own terms were not confronted with this dilemma. Over time, they had incorporated their paraplegia so successfully into their lives and being that it ceased to be anything other than ordinary for them. Whilst they might retain their sense of difference, they perceive and constitute themselves as boringly normal human subjects:

**What does paraplegia mean to you?**
It used to mean a lot to me ...because I looked at myself as being different I suppose. But now ...being a paraplegic doesn't mean a lot to me because I look on myself as being a normal person.

**You no longer see yourself as being different?**
No.

**You are different but it doesn't stop you?**
Yeah. That's right. That's the one....My main outlook is that I'm just a normal person. (m,17,5)

I don't even think of the chair under me. I see myself as a person. (m,18,7)

The sentiments expressed in the last quote are representative of those who said they had not changed as a result of their paraplegia. That may well be true, but I suspect that such
people have organized their lives around their paraplegia so successfully that it ceases to be an issue for them.

Summary

In this section, the constitution of self and subjectivity was examined as an effect of the ways in which paraplegics were able to use their bodies within the framework of a gendered culture. Part 1 focused on sexual activity and the effects it had on the ways paraplegics constituted themselves as masculine and feminine subjects, as women and men. Part 2, focused on how paraplegia limits the ways in which paraplegics are able to deploy their bodies generally, and how this limits and shapes the choice of subject positions available to them within a gendered culture. It was noted that one way of increasing choice was for paraplegics to redefine masculinity and femininity in terms that aligned more closely with their physical capabilities. This allowed them to constitute themselves as boringly normal human subjects. However, while this may be a perfectly plausible strategy for individual subjects to adopt, the validity of so doing is ascertained within a cultural context and by the way other people evaluate and respond to one's behaviour and actions.

SELF: READING SOCIETAL PERCEPTIONS OF PARAPLEGIA

This section is structured around the notion that human individuals can only make themselves into a subject to the extent to which they have become an object, that is, a distinct entity in the eyes of others to which they respond (Burkitt, 1991:189). To this end, paraplegics were asked first, what they perceived societal perceptions of them as paraplegics per se to be; second, the social acceptability of paraplegia compared with other forms of physical disability; and finally, the importance of appearances when presenting self as a viable subject in an able-bodied world. These questions forced them to think of themselves more in terms of corporate identity than in terms of individual self-identity. In doing this, individuals were required to abstract from personal experience, social stereotypes, hearsay, and the stories of other paraplegics and, in so doing, turn self into an object. Hence, the received corporate identity must of necessity be an amalgam of personal experience, fact, and idiosyncratic interpretation which reveals as much about an individual sense of self as corporate identity.
Reading society

In their readings of society a minority of paras believed that the ‘disabled’ stereotype was universally applied with paraplegics generally being cast as inferior: 'As cripples, people to be pitied, lesser people, people whose situation they never want to be in - quite patronizing sort of attitude towards us really!' (f,22.5). In a similar vein, another focused on the infrastructural and personal discrimination paraplegics faced daily in living in a society designed for and by non-disabled people:

I find Society cruel...towards paraplegics ...some things aren't made easy....Like why paraplegic's parking is on the left side instead of the opposite side so that you could get your chair up onto the foot-path....Why kerbs are so different in sizes ...all the barriers they throw up at you. And how people sometimes look at paraplegics. (m,20,2)

With new building codes in place and the growing institutional awareness of the needs of disabled people, questions of access should gradually become a thing of the past. At two years paralysed, this para was still overly self-conscious in public, still noticed, had yet to incorporate the 'stares' into his being so that he no longer noticed or worried about them. In short, it takes time to enselve the paraplegic body totally, to make the abnormal normal. Yet he had already developed a key survival skill, that corporeal literacy which involves reading bodies and demeanour in order to discern willing and able helpers:

... I think being a para you learn to find the good will in people to help you. And those that won't....you're easier [able] to pick up on senses....I've gone somewhere and I've just looked at people and I've clicked onto one person that would be willing to help and those that aren't....So your senses have improved. (m,20,2)

At this point a shift towards the middle ground is discernable. A number of paras expressed the belief that all sorts of views and attitudes towards paraplegics were to be encountered within society. A pithy summation of this position was given by one para when he said: 'There's a lot of good people in the world and a lot of bad out there too. Most are OK, some are ignorant ...some are outright arse holes' (m,38,16).

The majority of respondents were quite generous in their assessment of societal views and treatment of paraplegics or wheelchair users generally. For some, it was a question of an increasing population density, 'I think people are more aware these days of paraplegics and their condition because of more exposure and numbers....people do their best to understand and help' (m,23,7). For others, this understanding and help was, however, always
conditional, '...as long as you are trying, society has a pretty positive outlook on wheelchair users' (m,19,2). Another para advanced a different thesis:

Well I think they have a lot of compassion for them [paraplegics] really. They see them as [a warning] ..."if it ever happened ...I just don't know how I'd deal with it." They sort of look at it as ...like conquering a mountain ...when really, we know that if it happened to them, they'd be just like us and they'd get along with it. 'Cos life goes on and it's amazing how life is in the mind and not in the body and how you learn that when you're in a wheelchair.... (m,19,8)

While echoes of freaks conning rubes resound in that statement, it is worth considering that, perhaps, paraplegics are heroes? Maybe they have conquered metaphorical mountains? But they just don't see it that way because life calls, and to live means re-embodying self, re-enseling the paraplegic body, re-mind-ing it, consciously, mechanically doing for it those bits and pieces that the autonomic nervous system once did. In making the abnormal normal, the prosaic self, in terms of paraplegic subjectivity, emerges. Now, while living the paraplegic body quite automatically (a paradox in itself) might well be the stuff of heroes it is also a double-edged sword. The previous speaker continues:

... But ...society unfortunately ...do[es] see us as someone to be cared for and looked after. And who, maybe, can't do everything themselves....You do get grouped into the mass disabled bracket which means mental as well as physical. That's the biggest drag. (m,19,8)

According to this para, society sees paraplegics as heroes, albeit flawed-heroes, as people in deficit, lacking. And the real danger of this is that they are lumped in with the less salubrious forms of disability. Consequently, the paraplegic as object is devalued, negatively stereotyped, made less acceptable in normal society with negative consequences for the individual paraplegic subject.

**Locating paraplegia on the disability hierarchy**

Having already noted that many paraplegics tend towards stereotype when speaking about disabled people (p.201), I was interested to see if they believed that paraplegia was a more socially acceptable form of disability than other forms of physical disability.

The overwhelming majority of paras thought paraplegia was most acceptable because paraplegics looked normal, could communicate clearly, posed few problems ontologically, and because of our non-disabled socialization:
Yes. Because of appearance. Because a paraplegic just looks like a normal person sitting in a chair whereas somebody who's physically deformed doesn't look normal. So yes. (m,18,14)

Society cannot handle a person sitting in his wheelchair with his arms all crooked and dribbling at the mouth....you could be the most intelligent person you have ever met, but ...society is looking at it from the outside, not the inside. (m,30,8)

Some disabilities, yes. At least you can hold a conversation with us which is more than with some IHCs. Someone with brain damage. Spastics are pretty hard to talk to. (m,21,6)

Because it is not congenital therefore people don't seem so shocked. They can relate to accidents & [sic] paras look fairly "normal" (m,23,7)

Because our physical appearance seem less disabled as others. Also your thoughts & [sic] values are virtually the same (f,25,9)

In terms of socially held disability stereotypes, these paraplegics believed that paraplegics are looked upon quite favourably. In appropriating such a high ranking, these paras were constituting themselves within a positive corporate identity. This does not necessarily mean that they automatically constitute themselves positively as individuals, but that at worst, they could be thankful for small mercies, that is, there is always someone who is worse off. The quotes also highlight the importance of bodily appearances, its shape, control, demeanour, for social acceptance. While the paraplegic body always remains paralysed, a number of paras stressed the importance of dress in making it more acceptable, in manipulating others' responses.

Appearances

In Chapter II a brief history of the tendency to read inner self from outer appearances, to ascribe character to body shape, was outlined. An excavation of the disabled subject followed (Chapters III and IV) by focusing on the ways in which the anomalous body has been interpreted and understood in Western society. Using Foucault (1977, 1979, 1980, 1982) it was noted that since the mid-nineteenth century the anomalous body had become increasingly subject to medical control and produced as a disabled subject, that is, the negation of able-bodiedness and able-mindedness. However, traumatic paraplegics are not totally subject to negative social production but are able to negotiate and manage meaning.
and social identity\textsuperscript{10} in terms of how they present self in everyday life (see Goffman 1968, 1969).

A number of paras spoke about the care they took in managing outer appearances in terms of how they dressed and presented in public. The thoughts of three paras on this subject follow. The first speaks of the reality of the appearances of the paraplegic body:

...I never actually got to see what I looked like so there were never any mirrors around till I actually unpacked my mirror. So the first time I saw myself was about a month ago and I was just shocked [by] ...this sweaty mound of flaccid flesh. I always thought I looked like an ordinary person sitting down, but I don't. I've got this puku [stomach]....that came as a bit of a shock really. (f,22,1.5)

Such dawnings might come as a bit of shock to one personally, but this does not mean that the person need conform to stereotype:

I make a real effort to make sure I dress not like a disabled person. You know what I mean don't you? In your track suit and your fluffy slippers....Like the locals say "You don't look like you should be in a wheelchair." ...that's rather an interesting thing, isn't it? (f,26,10)

With a bit of sartorial care and attention, appearances can be managed to shape interactions with non-disabled people to one's advantage:

I think appearances play a big part, you know, how you dress. A lot of paras, a lot of disabled people forget about their appearance, which, from an able-body's point of view, is visual. How they see a disabled person is how they react to them. Some people do dress slovenly ...they don't dress well and that can be repulsive to an able-bodied person .... (m,22,12)

This para is advocating good dress sense as a kind of negation of the negation. Tidy outer appearances will clothe, disguise, ameliorate the discomforting aspects of the paraplegic body, allowing the subject pass as near enough to normal as possible.

It is clear from the above, that a number of paras cannot or do not separate self entirely from outer appearances. This ethos was captured succinctly by the para who said, '...I'm

\textsuperscript{10} Erving Goffman (1968) in \textit{Stigma: Notes on the Management of Spoiled Identity} distinguishes between a 'virtual social identity' and an 'actual social identity' (1968:12). The former refers to how individuals see themselves and the latter to how others see them.
reasonably self conscious about...how people take me when I'm sitting in my chair. Make sure I dress well. Got self-respect for my body from an outward point of view' (m,19,8).

Wheelchair semiotics
In Chapter VI it was argued that the boundaries of the paraplegic body change radically to include the wheelchair. Clearly then, the wheelchair is much more to the paraplegic than just a metal frame, seating, and wheels: it is something into which the paraplegic body grows, becomes organically articulated with. It can also be seen as something which is worn, as a fashion item. With the advent of new super-light, super-strong, space age alloys the wheelchair has been pared down, made sleek, more manoeuvrable, quick, and with it the paraplegic body-self. A greater range of paints and finishes have also become available, allowing more choice. Like the stars and starlets who use cosmetic surgery to carve their bodies into a shape consistent with desired persona (pp.56-8), paraplegics can now choose the chair in which they feel most at home. The iridescent paints, the brighter colours, the candy pinks and yellows, sassy purples, hot reds, sedate blues and greys, nihilistic black for young punks, are the cosmetic touches which transform the wheelchair into a statement of self. In this sense the wheelchair contributes positively to outer appearances; it has become a fashion accessory, a statement, hot property, chosen for effect as much as a means of mobility, a negation of the negation.

SUMMARY AND CONCLUSIONS
In this chapter, the constitution of self as a subject was examined in terms of the deployment of the paraplegic body within a gendered culture and the ways paraplegics interpreted societal perceptions and reactions to paraplegia and paraplegics.

The deployment of the paraplegic body was examined in two parts. Part 1 focused on sexual activity and the effects it had on the ways paraplegics constituted themselves as masculine and feminine subjects, as women and men. It was noted that the ways in which men and women are expected to perform as sexual subjects are (mostly) bounded by gender expectations based on sex. With paralysis, the gender expectations tied to the male sex are severely disrupted because of the physiological effects of paraplegia on sexual function. However, the distinction between sex and gender was largely ignored by the male paras in this study who mostly reduced their gendered notions of manhood and masculinity to
physiology, to bodily and sexual function. Hence, for some their sense of self as a 'real man', a truly masculine subject was, ultimately, seriously undermined, if not obliterated. For others, whose sense of manhood was not so dependent on achieving an erection, there was still a profound loss and deep sense of regret that they had lost the ability to copulate and beget their own children. Female paraplegics retain the biological capacity to procreate. However, they too experienced the effects of paraplegia in a gendered way as did males. It is just that they used different language to express this. For some female paras, womanhood was undermined by their incontinence, a loss of libido, sensation, and body tone. In contradistinction to the males who could no longer consider themselves as 'real men', none of these female paras expressed their experiences of profound absence and loss as a denial of themselves as 'true women'.

Part 2, focused on how paraplegia limits the ways in which paraplegics are able to deploy their bodies generally, and how this limits and shapes the subject positions available to them within a gendered culture. This involved a certain amount of 'bending the rules' and redefining masculinity and femininity so they moved closer to what was now physically possible. It was also argued that by virtue of what the paraplegic body can no longer do, and the strategies it must adopt to effect desired results, certain aspects of self, or multiple subject positions (see Kondo, 1990; Haber, 1994; Munford, 1995), are produced depending upon situation and context. The list - the lacking self, the frustrated self, the non-spontaneous self, the calculating self, the efficient and effective self, the fatalistic self - is by no means exhaustive. Indeed, it is a very skewed picture because it touches upon only the negative aspects of the paraplegic body, that is, what it cannot do as opposed to what it can do, and do productively. The reason for this, is that what the paraplegic body can do varies from subject to subject depending upon individual predilections, many of which were formed before paralysis. However, the effects of paraplegia are constant in terms of what the paraplegic body cannot do, so it made sense to examine these effects on individuals within a population for traces of a universal subjectivity, a paraplegic subjectivity, the paraplegic body-subject. This is not to say that this subjectivity is necessarily a totalizing subjectivity for all the individuals within that population. It cannot be, simply because of an individual's pre-paralysed socialization and the variety of pre-paralysed activities the paraplegic body can continue to do without interruption. This means that most elements of the subject's pre-paralysed world-view continue, that pre-paralysed norms and values survive paralysis, that the pre-paralysed self remains an important part of the paraplegic subject.
How comfortable one feels with an adopted or imposed subject position is, however, not just a matter of personal taste: it must be legitimated by broader social acceptance. Thus, the ways paraplegics constituted themselves as subjects in light of their readings of the ways others responded to paraplegics per se, were also examined. The majority view was that people and society were generally quite tolerant of or disinterested in paraplegics. These responses allowed/helped paras to feel O.K. about self. On occasions, this tolerance slipped into patronage which was reviled and generally not internalized as a component of self. Paras, almost unanimously, perceived themselves as being more socially acceptable than other forms of physical disability. Being the best of a bad lot was, however, cold comfort for some who argued that all forms of disability were socially unacceptable. In terms of appearance, a number of paras stressed the importance of dress in creating a good impression. Speaking in the same vein, a number of paras commented on how much better they felt in the new, lightweight, technologically advanced wheelchairs. Feeling less clumsy and less heavy, they constituted self in terms such as agility and quickness.

The accounts presented in this chapter suggest that the ways in which paraplegics constitute themselves as subjects are very much determined by physiological and social factors. Hence, the paraplegic self is best seen as the outcome of a process of complex interactions between corporeal, personal, social, medical and structural variables that are experienced and known as a 'paraplegic'. This new way of being is validated for the paraplegic subject objectively by observing societal responses to his/her being and actions. Subjectively, these new paraplegic ways of knowing and doing must be seen as standing in juxtaposition to pre-paralysed understandings of the same variables so long as they are remembered. Consequently, these memories are subject to subtle and not so subtle alterations over time: pre-paralysis experiences and self can be either romanticized or demonized. In either case, these memories, these pre-paralysed subject positions tend to be expressed in the phrase, 'I might be paralysed, but I'm still the same person.' This creates the paradox on which I conclude.
Chapter X

RESOLVING PARAPLEGIC SUBJECTIVITY AND THE 'I AM STILL THE SAME PERSON' PARADOX

What makes the study of the ways traumatic paraplegics perceive and constitute self particularly interesting, is that as formally non-disabled people they have most probably read disabled bodies stereotypically. They know disableist ideology and disableism: the interpretations, the expectations, the supposed, and often imposed, subjectivity accorded 'the disabled' by non-disabled society and the exclusions which follow. As traumatic paraplegics, however, they 'know' that such readings do not apply to them but to those lower in the disability hierarchy. Moreover, they know the world both as non-disabled and disabled people and, given the chance, they can operate comfortably in both worlds. Further, they have been subjected to the practice of medical and institutional power on them as specific bodies. A misreading of Foucault (1977, 1980, 1982) would suggest that a totalized subjectivity (the paraplegic subject) would emerge as the end product of the surveillance, discipline, and normalization the paraplegic body has been subjected to by various institutions (medicine, ACC, welfare). However, in this instance, such a reading would miss the point that traumatic paraplegics can resist the imposition of an institutionalized subjectivity from the vantage point of years of socialization as non-disabled people/subjects/selves/beings. And, mostly, they do resist. Precisely because of the negative consequences they know will accrue to their sense of self and life chances if they become, or are seen to be, one of the disabled.

The point is, that able-bodied subjectivity is not totally negated or that the subject reconstitutes self as totally paraplegic. Rather, the paraplegic constitutes self within a framework of multiple selves, multiple subject positions (cf. Kondo, 1992; Kennedy et al. 1993) depending upon situation and context. Hence, favourites (for example, colour, food) remain constant: the paraplegic will most likely continue to watch the same type of film, read the same books, keep the same politics, follow the same sport and so on, with the same expectations s/he had as an able-bodied person. But, in another context, when confronted with a flight of stairs or the contingencies of bladder/bowel maintenance, the paralysed body intrudes so much that the paraplegic subject dominates.

Non-disabled preferences will, of course, be subject to change, but change which comes with maturity, changing fashions, mixing in new circles, and so on rather than solely from
becoming/being a paraplegic. However, whatever one does, one generally does and experiences it differently from previous occasions simply because changes have occurred in one's life, changes which bring a new perspective to the event. The changes might be slight or radical (as in getting paralysed - and then with or without root pain) so that the event remains the same but different.

This means that there is not a sudden and total break with the subject's past. The subject continues to do and enjoy many of the activities it once did as an able-bodied person. Further, many of the elements of the subject's able-bodied world view continue: pre-paralysed norms and values survive paralysis so that the subject constituted in an able-bodied body remains an important part of the paraplegic subject. When this is taken in conjunction with disableism, the frequently voiced assertion - 'I might be paralysed but I'm still the same person' - is both understandable and not the paradox it might at first seem. It is a rejection of the limitations any totalizing subjectivity imposes on being and self; it is an assertion and claim to equality and fullness of being. The paradox is also explained by the feminist notion of multiple subject positions, or multiple selves within self (cf. Maynard, 1994; Munford, 1995) which may obtain at different points in time or '...at different levels of consciousness at a single point in time' (Kondo, 1990:224). In a note at the end of his response to the survey, a paraplegic explained the paradox:

Generally I do feel I'm the same person with the same thoughts but certain aspects of life are changed - body image, sexuality, general attractiveness to others....I feel my brain is the same but it may be difficult for some people to see what I'm really like. Physically I'm more diminished & this does have inevitable effect on the ego, although I don't always realize it. The problem is it's a long time since I experienced having a normal body so I've probably forgotten how good it was!...I don't have time to stop and think 'I'm a paraplegic.' Generally, I'm very happy although I don't know why I should be! I often just don't think about my disability but I think it is totally devastating and unfair injury ...accepting the condition is a matter of luck and is different from individual to individual....I don't think, as some people do, that those who put up with the injury are fighters & those who don't are weak and pathetic! In my case my current satisfactory existence was pure luck because of family support & my employer holding the job for me. Although I struggled along at first my life came together when I found I was feeling happier, not because of a determined effort to overcome the problem. (m,24,7)

If, as it has been argued, the paraplegic subject constitutes self in terms of able-bodied and paraplegic subjectivities depending upon situation and context, then it would be consistent to argue that the mix would vary from individual to individual depending upon any number of factors. The most important were age at time of accident, length of time paralysed, and
health status. Younger people had more to lose from paralysis so, initially, paraplegia was a more obvious and dominating part of their being. However, the longer they were paralysed and the more normal things they achieved (holding down a job, maintaining a relationship, travel) the more ordinary it became for them to be paraplegic. Younger paras were, thus, more intent on maintaining their sense of being a person before being a paraplegic than were older paras for whom the question had long ceased to be an issue. Over time, older paras had incorporated paraplegia into their being and subjectivity to a much greater extent: they had made the abnormal normal and paraplegia did not really matter. This is not to say that they unconditionally accepted their paraplegia but that they had just got on with life: they were simultaneously person and paraplegic, paraplegic and person, but, if pushed on the issue, were persons then paraplegics - the body could never be left out of the equation. On the other hand, paraplegics who lived with root pain, had chronic urinary tract infection, or were bedeviled with pressure sores, were subject to their paraplegia, were unhealthily paraplegic body-subjects. Unlike the previous group, who maintained that while paraplegics they were still the 'same person', these paras tended to constitute themselves in terms of their bodies, as 'a paraplegic first, then a person', a changed person, such that:

I think before the accident doesn't exist anymore....being a paraplegic is like being born again ...a new life, a new set of rules you've got to live by. I'm conscious of my health. Where before I wasn't, so the new rules are that you've got to be careful; you can't do what you want. (m,21,6)

Inevitably, with paraplegics, the body has the final word.
Appendix 1

METHODOLOGICAL ISSUES

Setting up the study
On beginning this study, I approached the Director of the Otara Spinal Unit, Dr O R Nicholson, seeking his support for the project. He was delighted that the study had been mooted and even more so that a former patient of his was proposing to undertake it: he gave his support unreservedly. He then introduced me to the secretaries, telling them of the study, and asking them to give me unrestricted access to patients' admission records. These contained names and addresses, age, date of admission, date of discharge, level of injury, marriage status, and ethnicity.

Characteristics of the sample
The records showed that 225 people with paraplegia were admitted during its first ten years of operation. Of these, 180 were admitted for the first time, the remainder for a variety of reasons directly related to their paraplegia, for example, pressure sore care. Of the former group, fifty-nine percent were between the ages of sixteen and thirty years, and the male to female ratio was four to one. Motor vehicle accidents accounted for sixty percent of injuries followed by work-related accidents, falls, and sports-related injuries. In selecting the interview sample I tried to reproduce these patterns as closely as possible, but was unsuccessful for a number of reasons. The prime reason was that not all people were available for interviews and the sample developing into a 'snowball' sample. As I travelled to various parts of the country I was given names and contact numbers of other paraplegics in the area. Upon making contact, explaining the objectives of the study, and the terms and conditions under which the interview would be carried out all agreed to be interviewed. Before each of these 'snowball' interviews were carried out the objectives of the study and areas to be covered in the interview were again explained to the subject who was then asked to sign a consent form before the interview commenced. The characteristics of the eventual sample are given in Tables 1.0, 1.1, 1.2, 1.3 in Appendix 3.

This pattern of SCI distribution is consistent with that in America and the United Kingdom which show that young men driving motor vehicles are the most at risk group when it comes to paraplegia (see Trieschmann, 1988:8; Creek et al.,:12).
Ethical considerations

An outline of the study and a copy of the proposed questionnaire was submitted to the then Auckland Hospital Board Ethical Committee for consideration. Approval was given with the proviso that the informed, written consent of subjects be obtained before any interviewing took place. No alterations to the structure of the questionnaire were required.

Data collection

Over a period of two years (1989/90) I explored these questions in face to face interviews with fifty paraplegics and via a postal survey of a further 130. For reasons of consistency the same interview schedule was used for both the interviews and the survey. These 180 people constituted the entire population of paraplegics rehabilitated at the Otara Spinal Unit in South Auckland during its first ten years of its operation (1976-1986). Of the fifty interviews carried out forty-eight were suitable for inclusion in this study. One interview was rejected because it was carried out under circumstances which militated against obtaining any useful data and the other because the person was more interested in my experience of paraplegia than in contributing in any substantive sense to the study. Of the 130 surveys posted, thirty were returned as 'not known at this address' and remained untraceable. However, forty-two of those contacted did complete and return the questionnaire. In, total ninety paraplegics² provided both qualitative and quantitative data on their corporeal and social experiences of paraplegia, the meanings they subsequently attached to paraplegia, and the implications experience and meaning had for then in terms of self-perception and subjectivity.

² That is fifty percent of the paraplegic population that had been rehabilitated through the Otara Spinal Unit between 1976 and 1986. This compares with a study carried out by six researchers in the UK over a period of at least 4 years. From a sampling frame of 550, seventy-seven, or fifty-six percent of those contacted, were eventually interviewed (Creek, et al., 1987: 31).
ORDINARY PEOPLE, ORDINARY LIVES?
A SOCIOLOGY OF PARAPLEGIA

A Survey of Paraplegic Experience,
Lifestyle and Self-Perception
Appendix 3
FREQUENCY TABLES

CHARACTERISTICS OF THE SAMPLE

<table>
<thead>
<tr>
<th>Table 1.0</th>
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</tr>
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<td>Sex</td>
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</tr>
<tr>
<td>Male</td>
<td>65</td>
</tr>
<tr>
<td>Female</td>
<td>25</td>
</tr>
<tr>
<td>N =</td>
<td>90</td>
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</table>

<table>
<thead>
<tr>
<th>Table 1.1</th>
<th>AGE AT TIME OF ACCIDENT</th>
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</thead>
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<tr>
<td>Age groups in years</td>
<td>N</td>
</tr>
<tr>
<td>&lt;16</td>
<td>6</td>
</tr>
<tr>
<td>16-20</td>
<td>27</td>
</tr>
<tr>
<td>21-30</td>
<td>29</td>
</tr>
<tr>
<td>31-40</td>
<td>14</td>
</tr>
<tr>
<td>41-50</td>
<td>9</td>
</tr>
<tr>
<td>51-60</td>
<td>5</td>
</tr>
<tr>
<td>N =</td>
<td>90</td>
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<table>
<thead>
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<th>LENGTH OF TIME PARALYSED</th>
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<tbody>
<tr>
<td>Time in years</td>
<td>N</td>
</tr>
<tr>
<td>&lt;1</td>
<td>4</td>
</tr>
<tr>
<td>1-3</td>
<td>22</td>
</tr>
<tr>
<td>3-5</td>
<td>16</td>
</tr>
<tr>
<td>6-10</td>
<td>30</td>
</tr>
<tr>
<td>&gt;10</td>
<td>18</td>
</tr>
<tr>
<td>N =</td>
<td>90</td>
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### Table 1.3
**CAUSE OF PARAPLEGIA**

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<thead>
<tr>
<th>Cause</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Road traffic accident</td>
<td>23</td>
<td>26</td>
</tr>
<tr>
<td>Motor cycle</td>
<td>19</td>
<td>21</td>
</tr>
<tr>
<td>Car</td>
<td>15</td>
<td>17</td>
</tr>
<tr>
<td>Work related</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Medical misadventure</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Fall</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Sports related</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Diving</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Medical</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Not answered</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>90</td>
<td>100</td>
</tr>
</tbody>
</table>

### HEALTH/BODY MAINTENANCE

### Table 2.0
**HEALTH PROBLEMS SINCE ACCIDENT**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary tract infection</td>
<td>44</td>
<td>68</td>
<td>21</td>
<td>21</td>
<td>65</td>
<td>72</td>
</tr>
<tr>
<td>Decubitus ulcer (pressure sore)</td>
<td>34</td>
<td>52</td>
<td>11</td>
<td>11</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>Root pain</td>
<td>17</td>
<td>26</td>
<td>8</td>
<td>8</td>
<td>25</td>
<td>28</td>
</tr>
<tr>
<td>Other*</td>
<td>12</td>
<td>18</td>
<td>10</td>
<td>10</td>
<td>22</td>
<td>24</td>
</tr>
<tr>
<td>Kidney related</td>
<td>6</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>

*Includes: severe muscle spasm, heavy sweating, exhaustion, and extreme fluctuations in temperature.

### Table 2.1
**READMITTED TO SPINAL UNIT OR HOSPITAL**

<table>
<thead>
<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>27</td>
<td>44</td>
<td>9</td>
<td>45</td>
<td>36</td>
<td>44</td>
</tr>
<tr>
<td>No</td>
<td>34</td>
<td>56</td>
<td>11</td>
<td>55</td>
<td>45</td>
<td>56</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>61</td>
<td>100</td>
<td>20</td>
<td>100</td>
<td>81</td>
<td>100</td>
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</tbody>
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Missing cases = 9
### Table 2.2
**REASON FOR READMISSION TO SPINAL UNIT OR HOSPITAL**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decubitus ulcer</td>
<td>11</td>
<td>44%</td>
<td>4</td>
<td>66%</td>
<td>15</td>
<td>48%</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>4</td>
<td>16%</td>
<td>1</td>
<td>17%</td>
<td>5</td>
<td>16%</td>
</tr>
<tr>
<td>Kidney/bladder</td>
<td>4</td>
<td>16%</td>
<td>1</td>
<td>17%</td>
<td>5</td>
<td>16%</td>
</tr>
<tr>
<td>Sphincterotomy</td>
<td>2</td>
<td>8%</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Perforated bowel</td>
<td>1</td>
<td>4%</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>Broken bones</td>
<td>2</td>
<td>8%</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>7%</td>
</tr>
<tr>
<td>Suicide attempt</td>
<td>1</td>
<td>4%</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>3%</td>
</tr>
<tr>
<td>N =</td>
<td>25</td>
<td>100%</td>
<td>6</td>
<td>100%</td>
<td>31</td>
<td>100%</td>
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</table>

Missing cases = 5

### Table 2.3
**HAVE USED ALTERNATIVE MEDICINE**

<table>
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<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>19</td>
<td>31%</td>
<td>12</td>
<td>50%</td>
<td>31</td>
<td>36%</td>
</tr>
<tr>
<td>No</td>
<td>43</td>
<td>69%</td>
<td>12</td>
<td>50%</td>
<td>55</td>
<td>64%</td>
</tr>
<tr>
<td>N =</td>
<td>62</td>
<td>100%</td>
<td>24</td>
<td>100%</td>
<td>86</td>
<td>100%</td>
</tr>
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Missing cases = 4

### Table 2.4
**STANDARD OF HEALTH BEFORE AND SINCE ACCIDENT**

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Before</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>66</td>
<td>73</td>
<td>16</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>14</td>
<td>16</td>
<td>18</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>10</td>
<td>11</td>
<td>28</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Neither good nor bad</td>
<td>-</td>
<td>-</td>
<td>14</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>9</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Very Poor</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>N =</td>
<td>90</td>
<td>100</td>
<td>90</td>
<td>100</td>
<td></td>
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289
**LEISURE AND RECREATION**

### Table 3.0
**PATTERN OF LEISURE ACTIVITY BEFORE PARALYSIS**

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mainly solitary</td>
<td>6</td>
<td>9</td>
<td>1</td>
<td>4</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>Mainly with friends/family</td>
<td>36</td>
<td>56</td>
<td>12</td>
<td>50</td>
<td>48</td>
<td>55</td>
</tr>
<tr>
<td>Mixture of solitary + group</td>
<td>22</td>
<td>34</td>
<td>11</td>
<td>46</td>
<td>33</td>
<td>38</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>64</td>
<td>100</td>
<td>24</td>
<td>100</td>
<td>88</td>
<td>100</td>
</tr>
</tbody>
</table>

Missing cases = 2

### Table 3.1
**LEISURE ACTIVITIES HAVE CHANGED SINCE PARALYSIS**

<table>
<thead>
<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>47</td>
<td>72</td>
<td>12</td>
<td>57</td>
<td>59</td>
<td>69</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>26</td>
<td>8</td>
<td>38</td>
<td>25</td>
<td>29</td>
</tr>
<tr>
<td>Yes &amp; No</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>65</td>
<td>100</td>
<td>21</td>
<td>100</td>
<td>86</td>
<td>100</td>
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</table>

Missing cases = 4

### Table 3.2
**CHANGES IN LEISURE ACTIVITIES HAVE AFFECTED CHANGES IN SELF-PERCEPTION**

<table>
<thead>
<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>16</td>
<td>34</td>
<td>5</td>
<td>42</td>
<td>21</td>
<td>36</td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>66</td>
<td>6</td>
<td>50</td>
<td>37</td>
<td>63</td>
</tr>
<tr>
<td>Yes &amp; No</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>47</td>
<td>100</td>
<td>12</td>
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<td>59</td>
<td>100</td>
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Missing cases = 31
### Table 4.0
**ADEQUATE LUMP SUM COMPENSATION**

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<th>Male</th>
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<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>20</td>
<td>35</td>
<td>7</td>
<td>32</td>
<td>27</td>
<td>34</td>
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<tr>
<td>No</td>
<td>37</td>
<td>64</td>
<td>14</td>
<td>64</td>
<td>51</td>
<td>64</td>
</tr>
<tr>
<td>Yes &amp; No</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>2</td>
<td>3</td>
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<tr>
<td><strong>N =</strong></td>
<td>58</td>
<td>100</td>
<td>22</td>
<td>100</td>
<td>80</td>
<td>100</td>
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</tbody>
</table>

Missing cases = 10

### Table 4.1
**ACC: FAIR DEAL OVERALL**

<table>
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<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>34</td>
<td>60</td>
<td>12</td>
<td>55</td>
<td>46</td>
<td>58</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>40</td>
<td>10</td>
<td>46</td>
<td>33</td>
<td>42</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>57</td>
<td>100</td>
<td>22</td>
<td>100</td>
<td>79</td>
<td>100</td>
</tr>
</tbody>
</table>

Missing cases = 11

### Table 5.0
**INCOME SOURCE**

<table>
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<tr>
<th>Source</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACC</td>
<td>21</td>
<td>32</td>
<td>14</td>
<td>56</td>
<td>35</td>
<td>40</td>
</tr>
<tr>
<td>Invalid benefit</td>
<td>13</td>
<td>20</td>
<td>1</td>
<td>4</td>
<td>14</td>
<td>16</td>
</tr>
<tr>
<td>DPB, widows, unemployment</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>8</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>benefit</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>National super</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>8</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Dependent partner</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>16</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Wages/salary</td>
<td>26</td>
<td>41</td>
<td>2</td>
<td>8</td>
<td>28</td>
<td>31</td>
</tr>
<tr>
<td>Wages/Salary + ERC</td>
<td>4</td>
<td>6</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>65</td>
<td>100</td>
<td>25</td>
<td>100</td>
<td>90</td>
<td>100</td>
</tr>
</tbody>
</table>

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### Table 5.1
**EFFECT OF PARAPLEGIA ON INCOME**

<table>
<thead>
<tr>
<th>Effect</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss</td>
<td>43</td>
<td>77</td>
<td>18</td>
<td>82</td>
<td>61</td>
<td>78</td>
</tr>
<tr>
<td>Rise</td>
<td>10</td>
<td>18</td>
<td>3</td>
<td>12</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td>No Change</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>56</td>
<td>100</td>
<td>22</td>
<td>100</td>
<td>78</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 5.2
**RECEIVING A BENEFIT EFFECTS ATTITUDE TO PAID EMPLOYMENT**

<table>
<thead>
<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>22</td>
<td>37</td>
<td>6</td>
<td>32</td>
<td>28</td>
<td>35</td>
</tr>
<tr>
<td>No</td>
<td>38</td>
<td>59</td>
<td>13</td>
<td>68</td>
<td>51</td>
<td>66</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>60</td>
<td>100</td>
<td>19</td>
<td>100</td>
<td>79</td>
<td>100</td>
</tr>
</tbody>
</table>

### EMPLOYMENT

### Table 6.0
**EMPLOYMENT STATUS: 12 MONTHS PRIOR TO PARALYSIS**

<table>
<thead>
<tr>
<th>Status</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed, full time</td>
<td>55</td>
<td>85</td>
<td>15</td>
<td>68</td>
<td>70</td>
<td>78</td>
</tr>
<tr>
<td>Employed, part time</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>23</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>12</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Never employed</td>
<td>5</td>
<td>8</td>
<td>2</td>
<td>8</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>65</td>
<td>100</td>
<td>25</td>
<td>100</td>
<td>90</td>
<td>100</td>
</tr>
</tbody>
</table>

### Table 6.1
**EMPLOYMENT RATE AS PARAPLEGICS**

<table>
<thead>
<tr>
<th>Status</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>36</td>
<td>56</td>
<td>10</td>
<td>50</td>
<td>46</td>
<td>55</td>
</tr>
<tr>
<td>Unemployed</td>
<td>28</td>
<td>44</td>
<td>10</td>
<td>50</td>
<td>38</td>
<td>45</td>
</tr>
<tr>
<td><strong>N =</strong></td>
<td>64</td>
<td>100</td>
<td>20</td>
<td>100</td>
<td>84</td>
<td>100</td>
</tr>
</tbody>
</table>

Missing cases = 6
### Table 6.2
**EMPLOYMENT RATE BEFORE AND SINCE PARALYSIS**

<table>
<thead>
<tr>
<th>Status</th>
<th>Before</th>
<th></th>
<th></th>
<th>Since</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>77</td>
<td>86</td>
<td>46</td>
<td>51</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>6</td>
<td>7</td>
<td>38</td>
<td>42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not answered</td>
<td>7</td>
<td>8</td>
<td>6</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N =</td>
<td>90</td>
<td>100</td>
<td>90</td>
<td>100</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 6.3
**EMPLOYMENT PATTERNS AS PARAPLEGICS**

<table>
<thead>
<tr>
<th>Pattern</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same firm, same job</td>
<td>9</td>
<td>15</td>
<td>2</td>
<td>10</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Same firm, new job</td>
<td>8</td>
<td>13</td>
<td>4</td>
<td>20</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Lost job, new job, new firm</td>
<td>12</td>
<td>20</td>
<td>-</td>
<td>-</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Found job</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>15</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Retrained, employed</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Retrained, unemployed</td>
<td>7</td>
<td>12</td>
<td>2</td>
<td>10</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td>Lost job, still unemployed</td>
<td>16</td>
<td>27</td>
<td>8</td>
<td>40</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>Early retirement</td>
<td>2</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>N =</td>
<td>60</td>
<td>100</td>
<td>20</td>
<td>100</td>
<td>80</td>
<td>100</td>
</tr>
</tbody>
</table>

Missing cases = 10

### Table 6.4
**WORK HARDER AS PARAPLEGICS TO PROVE SELF**

<table>
<thead>
<tr>
<th>Response</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>23</td>
<td>35</td>
<td>5</td>
<td>50</td>
<td>28</td>
<td>61</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
<td>34</td>
<td>5</td>
<td>50</td>
<td>18</td>
<td>39</td>
</tr>
<tr>
<td>N =</td>
<td>36</td>
<td>100</td>
<td>10</td>
<td>100</td>
<td>46</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 7.0
PARAPLEGIA INTERFERES WITH ABILITY TO DO WORK

<table>
<thead>
<tr>
<th>Degree</th>
<th>Male</th>
<th>%</th>
<th>Female</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A very great deal</td>
<td>21</td>
<td>34</td>
<td>3</td>
<td>12</td>
<td>13</td>
<td>15</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>17</td>
<td>28</td>
<td>6</td>
<td>25</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Only a little</td>
<td>15</td>
<td>24</td>
<td>6</td>
<td>25</td>
<td>21</td>
<td>25</td>
</tr>
<tr>
<td>None or not at all</td>
<td>17</td>
<td>28</td>
<td>5</td>
<td>20</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>Don't know</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>16</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>N =</td>
<td>61</td>
<td>100</td>
<td>24</td>
<td>100</td>
<td>85</td>
<td>100</td>
</tr>
</tbody>
</table>

Missing cases = 5

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