LIBERATING THE DISABLED IDENTITY:

A COALITION OF SUBJUGATED KNOWLEDGES

This thesis is presented by Rose Galvin BSc, BA (hons) for the degree of Doctor of Philosophy of Murdoch University 2004.
I declare that this thesis is my own account of my research and contains as its main content work which has not previously been submitted for a degree at any tertiary education institution.
My thesis explores the notion, originally developed by sociologists such as Goffman and Charmaz, that a person’s identity undergoes a difficult and painful metamorphosis in response to the effects of serious long-term impairment or chronic illness. I argue that existing methods of researching what I have come to call “the disabled identity” generally avoid a deeper exploration of the social context in which this kind of marginalisation occurs. To address this absence, I develop a research methodology which combines an intensive exploration of the personal experience of disability with a critical analysis of the social and historical context in which the disabling of identity occurs. I approach the former through grounded theory and the latter through a Foucaultian analytics of genealogy and governmentality. These are informed by the theoretical insights surrounding the “social model” of disability which claims that “disability” is not a physical problem based on personal tragedy but is a social imposition based on exclusion and stigmatisation.

In accordance with this, the thesis proceeds in three successive stages. First, I apply a genealogical analysis to disability in general, then more specifically to the disabled identity, to provide the background for my qualitative research. The purpose of genealogy is to reveal that the concept under investigation is not a self-evident “given” but a social construction which has developed to serve varying interests over time. Through this process it becomes evident that disability has evolved as a concept which performs as a counterpoint to the norm and, as such, provides a measure of “what not to be” in terms of contemporary neoliberal citizenship.

Next, I engage in a grounded theory study which draws on the stories of disabled people to explore how their self-perceptions and the attitudes of those around them have been affected by disability. These stories stem from a variety of data sources, including my dialogues with participants, written stories from participants, and published autobiographies. Their analysis results in the emergence of the following themes: independence, occupational identity, and sexuality/appearance. Each theme is discussed in a separate chapter which attempts to let the stories speak for themselves by way of lengthy excerpts from the participants and texts, and combines them, where relevant, with my own insights and experiences as a disabled person.

In the final stage, I use a governmentality analysis to explore these themes and to place them in their current social and historical context. Here I suggest that independence, work and sexuality are key factors which are used to divide the affiliated from the marginalised in contemporary neoliberal societies. I argue that the two “technologies” which currently have the most impact on how independence, work and sexuality are governed in relation to disability are welfare reform and sexual rehabilitation. Here I explore the available primary sources - particularly the last five years of Australian government policy on welfare reform and a selection of sexual rehabilitation texts - to reveal how governance seeks to operate as a liberatory force while remaining oppressive due to its paternalism and reinforcement of normative prescriptions.
The final chapter further problematises disability in relation to the governmental concepts of “self-esteem” and “empowerment” in an attempt to unpick what can be claimed to be emancipatory from what remains embedded in the dominant discourse. By ‘deconstructing necessity’ and exploring the root causes of oppression through what Foucault refers to as ‘the disinterment of subjugated knowledges’, the thesis outlines an alternative discourse in relation to “disability” and opens up new possibilities for the creation of more positive identities.
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Publications Stemming From Thesis Chapters

The following papers have originated from the early drafts of my thesis chapters.


Galvin, R. (2005) Researching the disabled identity: Contextualising the identity losses which accompany the onset of impairment. *Sociology of Health & Illness*, 27(3): 393-413. [Focuses on describing the grounded theory component of the research, covered in Chapters Five to Eight, but incorporating, in the discussion section of the paper, the Foucaultian analytics which frame all the other chapters].
Acknowledgements

Above all I would like to thank my supervisor, Professor Trish Harris, who has guided and helped to inspire my work for the last 6 years. It is mainly luck that brought her into my life as I am a distance education student and have not had the opportunity to meet any of the staff members at Murdoch. Ian Barns, the Programme Chair of my undergraduate degree, was extremely encouraging throughout and suggested that I should fast track to post graduate level by doing honours and applying for a PhD scholarship. Ian recommended Trish as a possible supervisor for my honours thesis and I could not be more grateful for the appropriateness of his choice. After one very inspirational and heartening phone conversation, we fell into the pattern of email communication which has continued to greatly impact upon the design and direction of my work. At the outset of my honours research, Trish gave me both the confidence to believe that my raw ideas formed the heart of a strong and worthwhile thesis and the theoretical framework within which to develop it. My current thesis builds on the insights developed during my honours work and it would not have taken the shape it did without the extensive email dialogues I had with Trish in early 2001. Added to academic support, Trish offers a very human quality to the process. Unlike the supervisor of one my friends, who was reported as saying, ‘I don’t do pastoral care’, Trish is prepared to help her students weather the combination of difficulties which inevitably trouble the process of engaging in a dissertation. I think my concluding comment in the email I recently wrote in relation to her editing says it all. ‘You are an angel (who wields the slickest and sharpest pruning sword in the West :) :) )’.

Another person without whom my project seems inconceivable is my friend and colleague, Rebecca Caines. We have been working on our dissertations over the same period and much of the insight which frames what I believe is most meaningful in my work has come from our conversations and our combined desire to make our work, above all else, liberatory. Added to the countless ways in which she has supported me throughout with her insight, understanding, encouragement and love, Rebecca is currently proof-reading my final draft with such an intense regard for detail that I can relax in the knowledge that it will be the polished product I desire.

There are many others without whom my research would not have been possible and foremost amongst them are my participants, those people who were prepared to revisit very painful areas of their lives in order to share their stories in the belief that they may help to make a difference. I have been honoured to meet these people, all of whom in variety of ways have demonstrated what has become one the most powerful themes to emerge from my research, that disability can ultimately engender a transformation of world view and inform new, more liberatory ways of being in the world. Here, Lesley Tyzack deserves special mention because her belief in my work, her support in finding me a diverse array of participants in New Zealand, her powerful effect as role model and her ongoing friendship have had an enormous impact on both my research and my personal experience of disability.
Finally, and most significantly in all the ways that matter most, I would like to thank my partner, Leigh Caines, whose love, belief in me and endless practical support have acted like both balm and fuel. Anyone who has attempted a dissertation knows how obsessive, distracted and, at times, downright crazy it can make you. Leigh has weathered all of my “thesis behaviour” with a smile, sympathy and a constant stream of reassurance. Added to this, his lateral thinking and willingness to do anything to help has made the impossible possible, time and time again. So it is with love and immense gratitude that I dedicate my thesis to you, Leigh, because every day, in every way, you helped to make it happen.
INTRODUCTION

How could this happen to me? My image of myself, constructed with effort to live, to survive, to face others - with its inevitable share of masks and pretences, with the no less inevitable and necessary repressions - blurs, trembles, even cracks. I thought I was like this . . . and look what I've become! I thought people saw me like that . . . and look how I'll seem now! I thought myself charged with life, rich in potential . . . and look what I've produced! I have to start all over again . . . and in solitude, even if I am surrounded. Because it is my vision that is being wiped out - with its illusions and its reference points - and no one can understand or reconstruct it for me... Friendships, acquaintanceships, even those that were sincere and rewarding, come undone. Our loves - even if we thought them without end - bend and sometimes break. Personal confidences are lost. Ideals and facile hopes erode. And then, when hope is reborn, when the taste for life returns, when new relationships are formed, it is not without a bitter smile that I hear again talk of happiness or the announcement of brighter futures. Nothing, nothing, is left but a vague and cold tension not to fall apart. I face my fear (Stiker 1999: 2).

Being me in a changed image almost became unbearable. Except the image did not belong to me. It was created by the external world as if it wanted to obliterate the original version of me. My unique pattern was redundant - surplus to requirement. The past was irrelevant. Never mind that my spirit - my very essence - thrived on physical expression. My relationship to the world and the thing which gave it meaning was translated through the physical. . . My internal world was imprisoned with all this unexpressed movement. I had lost my dominant language and had not yet learnt the new one (Slack 1999: 29).

The four most far-reaching changes in the consciousness of the disabled are: lowered self-esteem; the invasion and occupation of thought by physical deficits; a strong undercURRENT of anger; and the acquisition of a new, total, and undesirable identity. I can only liken the situation to a curious kind of "invasion of the body snatchers", in which the alien intruder and the old occupant coexist in mutual hostility in the same body. It is also a metamorphosis in the exact sense (Murphy 1987: 108).

Each of these excerpts represent an attempt to describe the feelings of overwhelming loss which accompany the onset of disability, feelings that I identify with as they are an intensely accurate description of my own experience of disability. What they share is the recognition that disability involves not only the physical limitations that are associated with a body that ceases to function in an ordinary way, but that it also constitutes an identity crisis which severs the disabled person's sense of self from its former anchorage. This is hardly surprising: after all, who are we if we cannot do or be all the things which once defined us? Thus, the disabled person needs to learn to do and be other things, to develop a new identity to accommodate his or her physical limitations. What isn't so obvious, however, is how this process is engineered, how it is embedded in a social, political and historical context which governs its existence. This
is where I diverge from mainstream, professional responses to disability. I propose that the identity loss which results from disablement, far from being a psychological reaction to physical loss which can be remedied by the adoption of individual coping mechanisms, is in actuality created by a social system which privileges some people at the expense of others.

My desire to research this topic from this particular angle emerges, firstly, from an academic perspective grounded in the belief that our identities, whether they be defined in relation to gender, race, age or disability, are socially constructed, and, secondly, from my own personal experience of disability. This combination of factors, the social and the personal, informs my work at every level. I am disabled and a woman and recognise that this disempowers me on certain levels, but at the same time I am a white, middle class, tertiary educated person living in a wealthy Western country and I acknowledge that this privileges me over and above most people in the world. I have come to see that it is vital to take into account how this combination of positions constructs how I see the world, the research I chose to undertake and how I will perceive the data at my disposal. Rather than believing, as I was once encouraged to do, that these particularities must be excised in their entirety from my perspective as a sociological researcher, I now realise that my work will be enriched by their inclusion. Moreover, it is now my contention, inspired in particular by feminist research methodology, that it is farcical to pretend that it is possible to do otherwise.

I will reserve my discussion of the epistemological significance of a subjective approach for Chapter One where I will be outlining my overall methodology, but I feel it is important at this point to share the parts of my personal story which are relevant to my research. In 1983 I graduated from Hawkesbury Agricultural College with a degree in applied science and a desire to grow things. My qualification and my choice of occupation had a definite bearing on how I was ultimately to deal with the onset of disability seven years later. Firstly, science had attracted me as a field of knowledge because it promised to furnish me with the answers to all my questions and initially it didn't disappoint me because it appeared that, via the application of the scientific method, I could be sure to discover the truths behind many of life's mysteries. And, secondly, my career choice in horticulture was based on a desire to lead a very physical life which reinforced an identity which was already heavily reliant on strength, agility and a sense of communion with the outdoors.

When I eventually sustained a severe and permanent back injury through my work in 1990, my distress stemmed from my losses in both areas. The most immediate loss revolved around my incapacity to be physical in the ways I always had been which led to the loss of my occupation, my hobbies, my home, my pets, my garden, access to my friends (and some friendships altogether) and most of all I lost myself. My partner gave up on me and I was shunted off to my childhood home at the age of 32 to live with a mother who was already struggling to care for my father who was seriously disabled due to a stroke. My life was shattered and by far the worst
part of the experience for me was that no-one understood. I was completely, utterly alone and from behind the sheet of glass that separated me from the rest of the world I could not make myself heard. I had become, to all intents and purposes, invisible, without a voice and it is this kind of isolation that I want to break down by inviting disabled people to raise their voices through my research.

My other great loss, on an entirely different level, was that science had failed me. Not only was medical knowledge unable to help me to heal, those who practiced its arts were singularly unsympathetic and came to judge me harshly for the ongoing nature of my condition. But, more than that, the application of positivist science to my problems only served to render me even more helpless in the face of them. For the answers didn't lie within the blacks and whites, truths and falsities of the science that I knew; they existed in the blurred and murky regions of humanity which defy simple explanation. I began to study within the social sciences because I had always been interested in why people are the way they are, but, while initially I was attracted to the field of psychology because of its individualist focus and its scientific rigour, I gradually found myself seduced by the more subtle and complex explanations and explorations that were possible through the disciplines of politics, philosophy and sociology. By applying an interdisciplinary perspective within this area of the social sciences I was no longer stuck with such scientific "proofs" for "facts" such that men are more rational than women, that chronic pain is a behavioural problem, and that illness, poverty and rape are matters of individual responsibility. I had, conversely, entered a field that allowed for the understanding of personal problems as socially created and politically remediaible.

Indeed, through the development of an understanding of the ways in which personal experience is grounded in social structures, I have discovered the remedy that medicine denied me. For it has been my experience that to unearth the social origins of our personal problems can allow us to let go of the feelings of guilt and shame and helplessness that are part of owning a negative identity and to provide the tools for challenging it. This belief forms the heart of my research and designates the shape and the direction it must take. To be able to effectively explore the development of the "disabled identity", and to devise mechanisms of resistance which promise to loosen the ties that bind us to negative self perceptions, I believe that it is necessary to move beyond the current methodological dichotomy which necessitates making a choice between a macro- and a micro-sociological approach. I will be arguing that it is necessary to combine both these approaches because this will create the means for joining the insights that can be gained from a structural analysis with the voices of the people whose lives and experiences form the subject matter being studied.

It is not my intention to give a detailed description of the new road I take with my methodology here because Chapter One will be dedicated to this task and I wish to use this opening section to discuss matters concerning definitions and boundaries and to describe more clearly what I
aim to achieve with my research. But, for now it will suffice to say that, by combining a Foucaultian analysis of the social and historical context in which disability has been constructed with a qualitative research design which aims to delve into the experiences of disabled people themselves, I hope to provide an analytical lens through which disability can be viewed in its dual contexts as both a social imposition and an experience of deep personal loss.

At this point it is necessary for me to clarify what I mean by "disability". I originally believed that this would be a relatively simple task because I subscribe to the definition which is specified by the social model of disability (see, for example, Barnes 1998a; Oliver 1990; Priestley 2003). According to this perspective, "disability" does not refer to the physical incapacity usually defined in this way, but to the state of social disadvantage which has come to accompany it. However, although my thesis will be dedicated to demonstrating that an understanding of disability as a social construction rather than a physical reality will make it possible to challenge its oppressive consequences, there are times when I need to use the word "disability" in something like its conventional sense. For example, when I explore the historical evolution of the concept of disability in Chapter Two I am mainly referring to the development of the term and its associated meanings as they have been traditionally understood. It is vital that I do this as, if I attempted to replace "disability" with the word "impairment", which is the social model's preferred descriptor for the physical problem which underlies the socially imposed disability, then I would not be tracing the ways in which the term "disability" has been constructed as an oppressive category.

I believe that my analysis of language in Chapter Three will help to explain that these problems are unavoidable because language is not a stable entity and the continual deferral of meaning which frames our linguistic heritage performs a necessary function in the development and usage of language. Therefore, in keeping with an awareness of the fluid nature of language, it is necessary for me to be able to use "disability" in two distinct ways: firstly, in its traditional sense as a category of physical malfunction which has served to divide those who can from those who cannot do certain things, and, secondly, in relation to a set of exclusionary conditions, attitudes and practices which are imposed on top of such physical conditions. Nevertheless, although I will be arguing, in keeping with the social model of disability, that disability results from the existence of social barriers which exclude people who are physically limited from full social participation, I must make clear that I diverge from the social model in two significant ways, firstly, by challenging its grounding in essentialist logics which, up until recently, has excluded identity from the realm of analysis encompassed by disability studies, and, secondly, by including chronic illness in the category of conditions which can be claimed to lead to "disability".

The purpose of the social model of disability has been to distinguish between the physical state of "impairment" and the socially imposed condition of "disability". This has proven to be a very
useful distinction because it has opened up the recognition that physical incapacity need not entail exclusion from the workforce or access to public spaces or the opportunity to live independently outside of institutions. However, I argue in Chapter One that the social model, by dichotomising social cause and personal experience, retains an essentialist perspective grounded in the liberal philosophical assumption that our inner worlds are private realms for which we are entirely responsible. This is a highly problematic theoretical stance, the ramifications of which are discussed in depth in Chapters Three and Four, because it denies the disabling consequences of many illnesses and impairments and can leave disabled people feeling responsible for their subjugation. I argue, conversely, that the internalised oppression and marginalised social status which accompany serious physical limitations are equally social creations and that they result in what I refer to as the “disabled identity”. Thus, in keeping with its constructionist foundations, I argue that the term “disabled identity” relates to more than the identity possessed by a disabled person, it points to an identity, a state of subjecthood and subjectivity, which has been disabled, incapacitated, rendered inferior by prevailing social conditions and attitudes.

I also feel it is necessary to challenge the tendency within the field of disability studies and the disability rights movement to exclude those who have chronic illnesses. In attempting to challenge the medicalisation of disability, social model theorists have gone to great lengths to divorce themselves from any association with illness (see Oliver 1996: 33-37 and Barnes, Mercer and Shakespeare 1999: 54). However, as Ahmad (2000) argues, 'although disability does not necessarily entail chronic illness, chronic illnesses are almost always disabling' (5). Furthermore, as Wendell (1996) points out, many more people 'are disabled by arthritis, heart or respiratory disease, or diabetes than by blindness and paraplegia' (20), and, as Bury (1997) states, 'though not all forms of disability are caused by chronic illness, most are' (120). Although these theorists appear to be using the terms "disability" and "disabled" in their conventional sense, I argue that these physically debilitating conditions provide the foundations upon which disability, in its social model sense, is built.

In my own case, my disability arises from both an impairment and a combination of chronic illnesses, and, like de Wolfe (2002) who laments that her inability to be vigorous and mobile like many of those who are at the forefront of the disability rights movement has made her feel that she cannot claim 'legitimate membership' (257), I too have felt that I have belonged in neither the world of the able-bodied nor the group which defines itself as disabled. Yet my physical state and its consequences are highly problematic. My back injury does not allow me to sit or bend or lift anything heavy, I need to spend most of my time lying down, and pain is my constant companion, fluctuating between a blinding agony that shatters my ability to engage with the rest of the world and a dull, throbbing ache which I try to ignore. The fatigue which is the legacy of a post-viral illness has been even more debilitating than my back injury in some ways because it severely compromises my ability to think and to communicate and, at its worst,
it makes the simplest task, like cleaning my teeth or walking to the mail box, absolutely exhausting. Yet, although my physical limitations are very different from most of the disabled activists and theorists I read about, I recognise that my problems have led to the same feelings of exclusion that have brought these people together in an acknowledgement of their shared oppression.

I see my task in the following chapters as attempting to derive emancipatory insights from a combination of poststructural analysis and qualitative research. I will endeavour to demonstrate that both elements are vital to the creation of a method of research which is capable not only of providing a deep structural analysis which does not fall into the modernist trap of claiming to represent universal truths, but which also utilises personal narratives to exemplify the political nature of individual experience, to contribute additional and alternative “texts” to the secondary sources which are usually the focus of poststructural analysis, and to help guide the structural component so that it retains a firm connection to the lived experience it is claiming to illuminate. I strongly believe that this methodological merger will be capable of foregrounding the social and political nature of what has otherwise appeared to be an entirely personal experience, and, by bringing to light the social construction of the disabled identity, I believe it will be possible to devise alternative modes of identity construction which do not rely on the existence of hierarchical binaries which privilege some people at the expense of others.
PART ONE

Methodology
CHAPTER ONE

Grounding Genealogy:
Questions of Theory and Method

The problem of disability is a bit like the shard of pottery discovered during an archaeological dig that justifies important observations on the culture of which it is the vestige. To change our imagery, it is a bit like the cliff-side view over a whole valley or the obstacle that tests the condition of the athlete or, finally, the barometric reading that tells us the weather (Stiker 1999: 172).

My reasons for choosing disability as the subject of my research are complex and most of them do not belong in a discussion involving methodological issues. However, I feel that it is necessary to open this methodological discussion by bringing to the forefront my contention that disability is more than just a "topic" or a research category. It is a pivotal cultural construction, the understanding of which, I believe, can provide the possibility for illuminating other research based on identity; challenge more broadly the sociological study of "personal troubles" in their social contexts; and unearth the largely unquestioned assumptions that frame our world views which stem from the interaction of scientific knowledge and the diffuse networks of power which govern our lives. This will be possible, I argue, because disability is part of a fundamental dichotomy which separates what is deemed to be socially acceptable from what is not and, as such, is a particularly pertinent position from which to better understand the divisions which exclude certain people from enjoying full and equitable participation in society.

While, as Meekosha (2003: 66) contends, '[w]ithin broader progressive social movements, the disability movement appears to remain both unimagined and uninvited', disability is gradually being accorded its place in sociological inquiries which focus on the issues of gender, race, and ethnicity (De Pauw 1996; Hill 1994; Barnes, Mercer and Shakespeare 1999; Vernon 1999). This has gone some way toward remedying the ableist assumptions which once rendered these movements discriminatory in relation to disability. However, I would argue that disability boasts an even more rudimentary significance as an organising concept than either gender or race, firstly, because at certain historical points it has been used to justify sexual and racial discrimination and therefore, in these respects, can be said to provide a common denominator for the understanding of oppressive identifications in general, and, secondly, it provides a unique position from which to explore the process of subjugation because those who acquire disabilities have been thrust from a more acceptable to a less acceptable social location and are thus privy to the dual perspective that this provides.

Baynton (2001) thus supports that, over the last two centuries, the attempts to rationalize the oppression of women and marginalised racial groups was made under the guise that they were disabled.
Disability was a significant factor in the three great citizenship debates of the 19th and early 20th centuries: women's suffrage, African American freedom and civil rights, and the restriction of immigration. When categories of citizenship were questioned, challenged, and disrupted, disability was called on to clarify and define who deserved, and who was deservedly excluded from, citizenship (Baynton 2001: 33).

It was women's supposed 'irrationality, excessive emotionality, [and] physical weakness' and the 'feeble-mindedness, mental illness, deafness, blindness, and other disabilities in particular races and ethnic groups' which were cited in defence of their exclusion. However, those who fought against these kinds of discrimination did not challenge the premise that disability was a valid justification for excluding people from political participation and access to social and economic resources (op cit. 34).

Disability, it would appear, has been synonymous with this kind of exclusion in the modern era and I argue that its construction is fundamental to other forms of oppression because they are ultimately based on the idea that certain people are biologically incapable of participating as fully fledged citizens. Accordingly, I believe that the category of disability, when understood as a fundamental conceptual tool for the analysis of current forms of oppression, needs to be given a central focus when developing methods for studying the social construction of subjugated identities. Wilson (2000) uses disability as the primary construct from which to critique contemporary science and argues that disability 'can become a "critical modality," a site and a methodology with which to investigate the mechanism by which scientific language, masquerading as technology, encodes and transmits a social agenda' (157). This is precisely how I wish to use disability in my research, as a critical modality which can bring to light the structure of our contemporary identities in such a way as to not only provide possibilities for liberating those who are "disabled" by society's view of them, but also those who, in striving to maintain their "normality", are similarly trapped within an identity which limits their possibilities for self-definition (Wendell 1997: 275).

I believe that the critical function which the concept of disability presently plays in structuring oppression can best be revealed at the point at which a person becomes disabled. This is what Denzin (1992) refers to as an 'epiphanal moment,' when a subject 'moves from one social world to another' (91). Denzin (1989) believes that the study of epiphanies or crises makes it possible to 'uncover [the] complex interrelationship between the universal and the singular, between private troubles and public issues in the person's life' (19), and it is this connection between what Denzin refers to as the 'biographical and the historical' that I wish to explore because I believe it can bring to the surface the deeply entrenched influence that disability wields in defining the boundary between who is accorded social privilege and who is not (33-34).
Hence, one of the reasons I am focusing on *acquired* disability is because I believe that becoming disabled results in an dramatic identity shift during which the person is 'between interpretive frameworks (Denzin 1992: 91). Denzin suggests that when this happens, experience is described in words which are yet to be contaminated by the cultural understanding of the new group' (ibid). I also believe that, in the longer term, this identity shift reveals both the norms which remained hidden and unquestioned before the person lost access to them and the opposing identity structure which is thrust upon the person when he or she becomes physically incapacitated. Moreover, the fact that disability can be imposed in adulthood is another factor which separates it from gender and race, both of which are socially imposed at birth. Hence, the onset of disability provides the same kind of potential for heightened awareness that would theoretically be possible for a white man who suddenly awoke to find he was black or a woman. This kind of Kafka-esque metamorphosis would allow the changeling to reflect on the privileges lost and the stigma gained from the downward exchange of social status. Yet, whereas a person does not suddenly, or at least involuntarily, change gender or skin colour, it is possible for disability to strike anybody at any time and it is this unique state of identity transformation which creates such a fertile location from which to study the process of subjectification.

**Healing the Rift Between the Personal and the Political**

A methodology which is capable of effectively exploring the construction of the disabled identity will need to move beyond traditional research paradigms because, although it can be shown that there has been a movement toward a more critical analytical framework, the study of disability still neglects to take both the social and the personal into account in a balanced way. What has occurred has been, in effect, a full one hundred and eighty degree turn from a purely individualistic focus which neglected to explore the social origins of disability at all, to one which has gone too far in the other direction, in that, although it gives due attention to the social barriers which function to create disability, it denies that the inner experience of oppression which accompanies disability is of social significance. What I will be attempting to do in this next section is to show where each of these approaches is lacking and to outline the requirements for the kind of research model which I believe will be capable of healing the rift between the personal and the political in disability research.

The methodology which has predominated in the study, and, I would add, the *creation* of disability since the early nineteenth century has been the positivistic approach adopted by medical science. Positivism is the hallmark of the objective, value neutral scientific method which is based on the belief that science is capable of discovering the "truth" about natural objects by studying them from a safe distance which does not interfere with their functioning. As Liggett (1997) argues:
For positivism, disability presents itself as a problem of definition. The issue becomes one of indicating the relevant physical impairment. A disabled individual is one who has some "medically" observable impairment; and medical science is not considered to be an interpretative system, but a value free mode of measuring physical impairment (181).

The medical model is criticised both by mainstream sociology for its lack of consideration of the subjective experience of disability and from within disability studies for its individualistic focus on disability as a personal tragedy rather than a social imposition.

In attempting to redress the limitations of the medical model, sociology has applied a phenomenological approach to the study of disability and chronic illness. This work, which has emanated primarily from the school of symbolic interactionism, has been of enormous value to the understanding of the experience of disability because it has gone beyond the functional accounts of medicine to an exploration of what happens to people's identities when they become disabled. Goffman's (1963) *Stigma: Notes on the Management of Spoiled Identity*, which analyses his observations on the effect that disability has on people's identities, and Charmaz's (1983; 1991; 1995) extensive qualitative research projects, which have given voice to hundreds of chronically ill and disabled people in regard to their experiences of identity loss and reconstruction, represent the seminal work in this field and have given us the personal stories which medicine shunned. This research provides invaluable insights into the worlds of those who have become marginalised due to disability, but nevertheless ignores the social and structural conditions which have systematically given rise to disability.

This individualistic focus has been contested from within the area of academic inquiry known as disability studies, a burgeoning field of social research which, like women's studies, has its roots in the civil rights movements of 1960s and 1970s. In developing the "social model" of disability, which provides a historical materialist account of the development of disability within capitalist society, disability theorists have redefined disability as "[t]he disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from mainstream social activities" (UPIAS 1976: 3-4). This distinction between "disability" as a socially induced condition and "impairment" as the state of physical incapacity which underlies it has opened the way for the development of an approach which can work towards social change because of the understanding that 'the fundamental issue is not one of an individual's inabilities or limitations, but rather, a hostile and unadaptive society' (Barton, 1999: xi).

In recent times the social model has been challenged from within the ranks of disability theory in relation to its essentialist claims about impairment (Patterson and Hughes 1997, 1999, 2000), its resistance to accommodating new ways of thinking (Davis 2000), and its neglect of the issues surrounding gender, race and ethnicity (Shakespeare 1999). I do not believe that these criticisms in any way spell doom for the social model. They can only contribute to the evolution
of disability theory in accordance with the conditions affecting liberatory movements within a postmodern society. As Corker (1999a) argues, instead of trying 'to stretch the social model further than it is intended to go' (Oliver 1996) with totalising claims about its explanatory power, we should view it as one strand in an emerging social theory of disability and consider that there may well be other strands, some of which have not yet been fully developed' (629).

It is my aim to contribute one of these strands by attempting to include the inner experience of disability within a methodological framework which is still founded on the social model's basic premise, that disability is a social construction which can only be challenged by working for social change. Yet, to do this I will need to disturb one of the fundamental assumptions on which the social model has rested. To remove itself from the individualism inherent in the medical model, it has been thought to be necessary to divorce the socially imposed "disability" from the experience of pain, suffering and inner turmoil that often accompanies "impairment". Barnes (1998b) refers to those who do try to cross the line into the personal realm of disablement as 'the true confessions brigade', a criticism which 'suggests that only collective analysis is "serious political analysis"' (Corker and French 1999: 6). Shakespeare (1992) expresses his concern with this: '[t]o mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is "really" about physical limitation after all' (40).

A growing number of disability theorists are beginning to form a cohesive platform from which to challenge the assumption that personal experience belongs outside the analytical framework of the social model (see, for example, Corker 1999a, b; Darling 2003; Galvin 2003a, b, c, 2004a, b, 2005; Humphrey 2000; Meekosha 2003; Thomas 1997, 1999a, b; Wan 2003; Watson 2002). In keeping with this critique, I argue that the traditional view of the social model, although focused on overcoming the individualistic assumptions of past disability research, threatens to remain trapped within the same suppositions that it is designed to critique. By claiming that individual experience is not socially relevant, the social model inadvertently aligns itself with the individualistic liberal paradigm which posits that our identities are stable, unitary entities which exist prior to our social experience and that our inner states are, therefore, a matter of our own responsibility. I, conversely, believe that our inner experience is built from within our social relations and am, therefore in complete agreement with Thomas (1999b) when she argues:

The psycho-emotional dimensions of disability are at least as "social" in origin as other "restrictions of activities" experienced in the labour market, in transportation, in education, in housing, in leisure pursuits, or wherever. Thus, spending most of one's time at home because one feels ashamed of a facial disfigurement, or not telling a boyfriend girlfriend about one's epilepsy for fear of a hostile reaction, are also manifestations of disablism alongside its more familiar consequences: not being shortlisted for a job, or not being able to get one's wheelchair into a shop (47-48)
I believe that the potential for healing the rift which has separated the social from the personal within disability research resides in the recognition that the social model needs to be redefined within a fully constructionist perspective. For, by acknowledging that our individual experience is heavily influenced by social forces, we can allow for a return of the phenomenological elements of lived experience to the social exploration of "disability" without sacrificing its commitment to emancipation through social change.

**Enter Foucault**

The methodological solution I will be proposing is based on my preference for poststructural theory and qualitative research methods, more specifically, Foucaultian analysis and grounded theory. I admit that they are unlikely bed fellows as, on the one hand, poststructuralism is based on the belief that the subject is "dead" because, rather than being the source of meaning, it is produced by discourses, institutions and relations of power (Danaher, Schirato and Webb 1996: 116) and that, therefore, the only worthy objects of analysis are texts. On the other hand, grounded theory stems from a symbolic interactionist perspective which has traditionally been wary of structural analysis because of its reification of the social and its subsequent exclusion of lived experience. I argue, however, that personal narratives are an equally relevant site for deconstruction because, as Mutua (2001) argues, "the human being is a text", a cultural construction which can be "read" in a similar manner to any other kind of text (106) and, consequently, the postmodern subject provides a rich source of the multiplicitous narratives which define situated individuality and are referred to variously as 'heteroglossia' (Bahktin 1986; Rabinow 1986), 'multi-dimensional textualisation' (Fischer 1986) and 'multi-verisimilitude' (Denzin 1997).

Conversely, there exists no inherent inconsistency in trying to apply a structural perspective to studies which are based on the principles of symbolic interactionism, because, although it has traditionally functioned as a micro-sociological site of research, its fundamental premise is that the 'self is not an object that has inherent meaning, but is a construct ... mediated by the relationships, situations, and cultures in which she or he is embedded' (Fine 1993: 82). Therefore, symbolic interactionism is a realm of theory which is ripe for the addition of poststructural analysis. Over the last decade, many theorists from within the symbolic interactionist school of thought have been arguing for a combination of agency and structure in their work. Attempts have even been made to create hybrid fields of study which aim to meld the two, such as, "interpretive interactionism" (Denzin 1992), "synthetic interactionism" (Fine 1993) and "late-modern interactionism" (Katovich and Reece II 1993) and, more recently, there has been an upsurge in the number of symbolic interactionist studies which seek to include poststructural insights (Castellani 1999; Clarke 1998; Gayne and Tewksbury 1999; Oliva 2000; Weisinger and Salipante 2000).
I differ from these researchers in that I am coming from a Foucaultian approach and, consequently, my analysis of power and social forces will remain paramount. In his extensive analysis of the creation of the modern subject through its interaction with the intensely imbricated structures of power and knowledge, Foucault provides a historical perspective which contextualises what is assumed to be necessary and reveals its contingency. In conversation with Foucault (1977 [1972]), Deleuze suggests that these modes of analysis and the theories they tease out are like 'a box of tools' (208) and it is from within this box of tools that I intend to select two of Foucault's most potent implements of investigation, genealogy and governmentality. I believe that grounded theory will complement these analytical tools so effectively because it is capable of translating the "texts" which are embedded in personal narratives into a format which can then be subjected to critical analysis. Each approach will feed into the other: the genealogical analysis will provide the historical context for the interviews, and the stories which emerge from the interviews will give birth to the themes which will be inserted into the governmentality component.

In keeping with their Foucaultian heritage, genealogical analyses and governmentality studies are methodologically similar approaches. They both allow for the historicisation of taken-for-granted concepts so as to situate them in their particular contexts, they rely on the belief that subjectivity is a construct which is mediated by power relations and systems of knowledge creation, and, by challenging essentialism, necessity and universal "truths", they open the way for other possibilities. Genealogy, however, involves a deep historical analysis which usually focuses on the emergence of the object of study in relation to several concomitant historical events - the rise of the administrative state, the birth of capitalism, and the development of liberal philosophy and positivist science - events which can be said to have merged to form modernity. Foucault (1988) stated that, by locating these kinds of concepts in their historical contexts, he wanted to explore how 'madness, sexuality, and delinquency may enter into a certain play of the truth, and also how, through this insertion of human practice, of behaviour, in the play of truth, the subject himself is affected' (48). Thus, by deconstructing scientific and philosophical "truths" and demonstrating their contingency and their immersion in vested interests, he aimed to explore the processes by which the modern subject has been created.

Governmentality studies are built from the insights which emerge from such genealogies, but they maintain a specific focus on contemporary political rationalities and how these influence individual behaviour through the subtle neoliberal technologies of individual self-management. They could be defined as a sub-category of the overall genealogical method because they draw from the historicisation of problematic concepts and intensify this contextualisation in relation to contemporary governmental structures. Their main difference, however, lies not in their analytical frameworks, which are very closely linked, but in the fact that, while Foucault personally undertook the major genealogical studies from which we draw most of our insights into his analytics of power, governmentality studies can be understood as 'a rather ambiguous
methodological legacy' (Stenson 1998: 335), an extrapolation of Foucault's (1991h) analytical insights with regard to contemporary forms of rule into a 'zone of research' which has been developed after his death (Gordon 1991: 2).

An example of a social research project which combines genealogy and governmentality is my analysis of chronic illness as an instrument of governance (Galvin 2000, 2002). This combination of Foucaultian modes of analysis provides a powerful challenge to the taken-for-granted nature of our notions of health and illness and, by unseating the scientific "truths" which have defined them, paves the way for other modes of thinking and acting. However, by not including the stories and the insights of the people I was researching I denied not only their potential to provide invaluable 'experiential data' for analysis (Strauss 1987: 10), but also the opportunity to utilise my research as a vehicle for the raising of individual voices, voices which have formerly been suppressed by the very social structures that were the focus of my analysis. I now conclude that while my work helped to illuminate an area which had previously received little attention, it could not be said to be emancipatory in anything but an abstract way.

It is this inadequacy that I aim to overcome in this thesis. I begin in Chapters One to Four by engaging in a genealogical analysis of the construction of disability in Western society and then, more specifically, of the disabled identity, an identity which I will argue has been created by social forces in keeping with particular institutional and governmental objectives. In Chapters Five to Eight, I build on the insights which have been generated in the genealogical phase by developing a qualitative research project around the concept of the disabled identity. Grounded theory is particularly suited to this kind of linkage because it is based on the belief that it is vital to acknowledge how one's theoretical stance, as well as one's personal experience, influence the research at hand, and it is geared toward providing categories of analysis which can become the fodder for theory generation. It is these categories which will indicate the most salient features of the disabled identity and will thus provide the areas of analysis for the governmentality phase in Chapters Nine to Eleven. In the rest of this chapter I will explore in more depth how each of these components of the thesis will function, separately and in combination. What I hope to achieve in bringing them together is not to create a methodological space which claims to generate universal truths but, as was Foucault's (1988c) desire, 'to present instruments and tools that people might find useful' in exploring the creation of the contemporary subject (197).

**The First Step: Historicising the Disabled Identity - [Chapters One to Four]**

It seems to me, that the real political task in a society such as ours is to criticise the working of institutions which appear to be both neutral and independent; to criticise them in such a manner that the political violence which has always exercised itself obscurely through them will be unmasked, so that one can fight them (Foucault as quoted in Rabinow 1991: 6).
An increasing number of disability theorists are beginning to include Foucaultian insights and analytics in their research (Campbell 1998, 1999; Corker 1998, 1999; Grosz 1991, 1996; Hughes 1999; Liggett 1997; Meekosha 1998; Price 1995; Reeve 2002; Tremain 2001). Their use of Foucault’s work range from brief references to more detailed utilizations of his insights into power, knowledge and subjectivity, but, so far, only Tremain (2001) has attempted to historicise disability within a genealogical framework. Tremain focuses on the contentious category of “impairment” and demonstrates that, in contrast to the social model view, impairment is inseparable from disability as a creation of biopower through which individuals are governed. I concur with Tremain and respond to her call for genealogical research on disability which functions as a ‘critical ontology of ourselves’ (632).*

A conventional, “history of ideas” approach to disability would assume that disability, because of its physical nature, has always existed in one form or another, and would attempt to outline its existence from early times, explore how it has been dealt with during these historical periods, and trace the ways in which medical discoveries have improved the lives of disabled people. Conversely, a genealogy or “history of the present” will not assume that disability is a natural physical category, but will explore it as a concept which has been immersed in a system of “truth” creation which interacts with power. The history traced by genealogy is not a stable, continuous progression but is rather ‘an unstable assemblage of faults, fissures, and heterogeneous layers that threaten the fragile inheritor from within and from underneath’ (Foucault 1991g: 80). A history of the present, according to Bunton and Peterson (1997),

directs attention to discontinuities and ruptures in thought and involves recognition of multiple determinations and the role of chance. It is a method that has an explicit theoretical and political goal: to disrupt the taken-for-grantedness of the present and to show how things could be different…. it is not an attempt to understand the past from the point of view of the present, but rather to disturb the self-evident present with the past (4).

Accordingly, genealogy does not seek to confirm the present by constructing a neat chain of events which are supposedly grounded in objectivist truths. Rather it attempts to shake up our complacency about what is, by intimating what could have been. It does not strive for neat solutions. It seeks to disrupt the very foundations upon which our beliefs, values and scientific “truths” lie. And, in exploring a concept such as disability, it will throw up questions, such as: Who has benefited and who has been excluded by the conceptual form disability has taken?
Within which discourses has disability been developed in this form? What would the world have looked like if disability had not been defined as an unacceptable physical difference?

Our traditional epistemological foundation is based on the belief that human beings are rational and that our inner natures can be tapped empirically by objectively determining the facts which underlie our psychological and physical nature. In contrast, through genealogy, ‘reason is revealed as only contingently so, neutral (scientific) knowledge is exposed as a massive exercise in power, [and] the unique individual is rewritten as a messy historical production’ (Brown 1998 38-39). Genealogy, then, is an ideal way of exploring the ‘messy historical production’ that is the disabled identity because it strips away the essentialist belief in an a priori self and reveals its conditional philosophical heritage.

An important starting point in the genealogical investigation of a particular form of identity is the recognition that the processes of subject formation are immersed in the creation of deep divisions between certain groups of people. Foucault (1982) coined the term ‘dividing practices’ to name one of the major ‘modes of objectification which transform human beings into subjects’ (208). The dividing practices which have been developed to separate, for example, ‘the mad and the sane, the sick and the healthy, the criminals and “the good boys”’ originated in the creation of institutions of exclusion such as leper colonies, asylums and prisons, but they have become increasingly subtle over time and are now operated primarily through processes of naming which are validated by science and disseminated through discourses and cultural forms (ibid). Indeed, I argue that the creation of the concept of dis-ability is a dividing practice within itself, for, by carving a dichotomous division between those who can and those who cannot participate fully in society, a naming practice is sanctioned which is designed to separate and, in fact, create those who Rose (1996c) refers to as ‘the affiliated and the marginalised’ (340).

It is the potential to be emancipatory which makes genealogy such a powerful tool for critical analysis. Without promising a liberatory theory which can reveal the real "truths" which have formerly been suppressed by power, genealogy provides a fluid space in which to create other "truths" (McNay 1992) and to ‘separate out from the contingency that has made us what we are, the possibility of no longer being, doing, or thinking what we are, do, or think’ (Foucault 1991f: 45-46). Genealogy is able to loosen the grip that functionalist accounts have over our perceptions and our apparent possibilities by exposing ‘those blocks of historical knowledge which were present but disguised within the body of functionalist and systematising theory’ (Foucault 1980d: 81). Therefore, instead of remaining trapped within the spaces carved out by conventional histories and scientific accounts, we can be given access to the histories which have formerly been masked ‘by functionalist or systematising thought' and become free to delineate other spaces for the development of self-understanding (ibid).
Even more important, according to Foucault, are the other forms of subjugated knowledges unearthed by genealogy, those which represent the individual voices silenced by hegemony. Foucault describes these in terms of ‘a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity’ (82). These are the suppressed voices of ‘the psychiatric patient, the ill person, …the delinquent’ etc., which are representative of ‘a popular knowledge …a particular, local, regional knowledge, a differential knowledge incapable of unanimity and which owes its force only to the harshness with which it is opposed by everything surrounding it’ (ibid). It is these voices that I wish to liberate and to draw from in the qualitative component of my research. For too long the functionalist account of the medical model has spoken for disabled people, molding them into objects of rehabilitation, people defined by their tragic losses and physical differences. I believe that the development of critical theory surrounding disability can map out a space from within which disabled people can speak.

Genealogy's potential to liberate lies in its capacity to disinter both forms of subjugated knowledge. Both 'the buried knowledges of erudition and those disqualified from the hierarchy of knowledges and sciences' need to be allowed to rise to the surface of critical analysis and to be developed in alliance for a new space of meaning creation to be made possible. Genealogy is, in effect, 'the union of erudite knowledge and local memories' (Foucault 1980d: 83). The next stage of my research, the phase which is focused on giving disabled people a voice, is not actually separate from the genealogical phase, it is an integral part of it, informed by the counter-histories which have been unearthed via the process of historicisation. As Foucault points out, what genealogy really does is ‘to entertain the claims to attention of local, discontinuous, disqualified, illegitimate knowledges against the claims of a unitary body of theory which would filter, hierarchise and order them in the name of some true knowledge and some arbitrary idea of what constitutes a science and its objects’ (84).

In Chapter Two I begin the genealogical process at the level of erudite knowledges by historicising disability in the modern era. I begin by combining the historical materialist perspective of the social model, which has revealed the emergence of the concept of disability as a form of physical malfunction serving to exclude the impaired person from work, with a Foucaultian analysis of how this act of categorisation has participated in the development of a normalising society. Chapter Three proceeds from this and narrows its focus to the investigation of the disabled identity. I argue here that the emergence of disability as a fundamental concept used to divide the affiliated from the marginalised in contemporary society has largely been due to the dichotomous structure of language itself. I seek to demonstrate that through an understanding of the semiotic, semantic and discursive structures of language it is possible to overcome these dichotomies by launching linguistic challenges. Chapter Four moves from language to culture and explores the problems involved with mobilising around a collective identity which is built from the same exclusionary logics as it seeks to challenge. These insights
into the historical roots of disability, the linguistic origins of the disabled identity and the problems inherent in claiming a unified site of oppression aims to provide a theoretical backdrop against which the narratives can be contextualised.

The Second Step: Giving People a Voice - [Chapters Five to Eight]

One of the features of oppression is the loss not only of voice but of the tools to find it (Zola 1994: 65).

In developing grounded theory as a methodological practice, Glaser and Strauss (1967) stated that one of their main aims was to narrow 'the embarrassing gap between theory and empirical research' (vii). It is now thirty five years on and I would argue that there still exists a cavernous gulf between the production of abstract theory and the reality of lived experience (Roulstone 1994; Thomas 1999b). I believe, however, that the key to reuniting theory and practice lies within genealogy's capacity to initiate 'an insurrection of subjugated knowledges' based on both the 'erudite' alternative histories that critical analysis can reveal and the 'naïve', local knowledges of formerly silenced individuals (Foucault 1980d: 81). The following discussion will be devoted to the exploration of the latter component. I will not be outlining the functional aspects of grounded theory as a methodology here as this will be dealt with in detail in Part Three. Instead I will be focusing on the methodological issues which stem from attempting to combine personal accounts with a poststructural analysis and on how these narratives perform a key function in forging a truly emancipatory research model.

In conversation with Foucault (1977 [1972]), Deleuze delivers a compelling argument for the inseparable nature of theory and practice. He believes that, in the process of their development, theories continually encounter obstacles which cannot be overcome without the theorist referring back to the practical objects being researched. ‘Practice is a set of relays from one theoretical point to another, and theory is a relay from one practice to another. No theory can develop without eventually encountering a wall, and practice is necessary for piercing this wall’ (Foucault 1977 [1972]: 205-206). Foucault makes it clear that his engagement with theory is only aimed at 'struggling against the forms of power' which 'block, prohibit, and invalidate' the knowledge of the oppressed, and, as both a critical theorist and an activist, his object was 'to create conditions that permit[ted] them to speak' (207). This made him wary of bringing theory and practice together because he felt that '[t]he role of the intellectual does not consist in telling others what they must do' (Foucault 1991a: 11) as this would involve a descent into the proliferation of absolute "truths", the very concept of which is antithetical to poststructural thought.

I concur with Foucault’s insistence that theory should not be used to create universalising prescriptions and that the role of the researcher should not be one of ‘complacency and
arrogance' (Moore et al. 1998: 97). However, in avoiding the elitism of the ivory tower, it is vital to recognise the need for a reversal of this "top-down" view of critical analysis and to acknowledge that personal experience is a vital component in the development of theory. In other words, the subjugated knowledges which exist at the level of personal experience can provide what Gill and Hertz (1999) refer to as 'rich mines of data' which are capable of being tapped to provide the raw material for critical analysis. Thomas (1999b) argues that 'personal accounts are singular in their power to illustrate and illuminate', and that they 'inject a down-to-earth quality into what would otherwise be a very abstract discussion of ideas and concepts' (7). Hence, although it may well be the case that we should guard against the hegemonic use of theory, this does not mean that, conversely, personal accounts should not be drawn on to great advantage in the development of theory.

Yet, Foucault's aversion toward any attempt to contain individual experience within the fixed boundaries of theory remains important. If the individual voices contained in personal narratives are claimed to represent an entire group of people, in this case disabled people; if the alternative "truths" which emerge are claimed to be absolute; if they are not understood to be "texts" which are themselves interpretations made within a particular social and historical context; and if they are filtered through hegemonic assumptions which suppress their capacity to speak outside of them, then these narratives are being viewed through a modernist lens which is at risk of 'recolonising and re-codifying' them. As Foucault (1980d) argues in relation to the subjugated knowledges unearthed through genealogy, 'those unitary discourses, which first disqualified and then ignored them when they made their appearance, are, it seems, quite ready now to annex them, take them back within the fold of their own discourse and to invest them with everything this implies in terms of the effects of knowledge and power' (86). And we, as theorists, are also in danger of using these recently disinterred knowledges to create our own universalising "truths".

I would argue, however, that these analytical difficulties need not necessarily be seen as weaknesses in the use of personal narratives, but, rather, as the foundations for applying a poststructural approach in their analysis. I believe it is possible to allow for the raising of individual voices within the field of critical social inquiry without inviting a collapse into modernist assumptions. To do so, it is extremely important to grasp the concept discussed by Couzens Hoy (1998) in relation to genealogy, that the outcome of analysis 'is the reinterpretation of what is always already an interpretation' (30). As Thomas (1999b) states in relation to her own research on disability:

Narratives are representations involving interpretation and selection in their construction (the "telling"), in their consumption (my "reading"), in their reproduction (my "re-presentation"), and in their further interpretation (your "reading") (7).
In a more classic sense, Denzin (1989) refers to this as the 'hermeneutical circle of interpretation' and argues that 'this means that scholars must state beforehand their prior interpretations of the phenomenon being investigated. Unless these meanings and values are clarified, their effects on subsequent interpretations remain clouded and often misunderstood' (23). And, I would reiterate, in keeping with this recognition, that it is essential to acknowledge that the narratives we are attempting to interpret are cultural texts which can be read in many ways. If we follow these methodological precautions, there is no reason why personal accounts should be not be considered as valid a site of analysis as written texts.

When personal narratives can be seen as cultural texts which, like all texts, have the power to illustrate, analyse, question and subvert, it is possible to see them as truly liberatory devices. As has already been argued, personal accounts can be emancipatory as they have the potential to inform theories which are capable of challenging the dominant knowledges which have formerly silenced the subaltern voices which are buried within the realm of subjugated knowledges. Yet, these narratives do not necessarily need to be fed back through a theoretical framework and processed via the interpretative practices of critical analysis to be emancipatory. Indeed, the telling of one's story can be liberatory in itself and it can be argued that the production of personal narratives has an extremely therapeutic effect on the "author" because it encourages a re-storying process which allows for the development of new forms of self-understanding.

hooks (1995), for example, who writes from a black feminist perspective, is a firm believer in the power of narrative and states that '[w]riting the autobiographical narrative enabled me to look at my past from a different perspective and to use this knowledge as a means of self-growth and change in a practical way' (7). In writing autobiographically, she sought to 'kill' the 'self' she used to be, the one who had been spawned from the pain of marginalisation, but instead she found that she 'rescued' this part of herself. In referring to this earlier self, she writes:

She was no longer the enemy within, the little girl who had to be annihilated for the woman to come into being. In writing about her, I reclaimed that part of myself I had long ago rejected, left uncared for, just as she had often felt alone and uncared for as a child. Remembering was part of a cycle of reunion, a joining of fragments, "the bits and pieces of my heart" that the narrative made whole again (ibid).

In a similar vein, Ware (2001) discusses the power of re-storying within pedagogic discourse. She has developed a course for disabled children in which they are encouraged to “rewrite their identities” through questioning their alterity, and White and Epston (1990) have been working within the field of psychology to develop what they call 'narrative therapy' which is designed to help their 'clients to re-author their lives, that is, to learn to think of their lives within the framework of different stories' (3). Furthermore, Weeber (1999a) has found within her qualitative research on disability that her participants have reported how 'reflection can deepen new insights' stimulated by the telling of their stories (107).
These alternative stories have the potential of being developed as 'counter-narratives', narratives which can be used to resist the dominant view (Thomas 1999b: 53). The development of counter-narratives is not a straightforward process because it is extremely difficult, some would say impossible, to speak outside of hegemonic discourse. However, in allowing for the voices of oppressed people to be raised in ways that have formerly been denied them, qualitative research provides the space for articulating this form of oppositional narrative and for helping to create the more positive identities they engender.

Perhaps the key point is that, without the counter-narratives of others who challenge social "norms" we, as isolated individuals, are trapped within the story-lines of the prevailing narratives. If we do re-write our own identities then we strengthen the counter-narrative, and the dominant and oppressive social narratives begin to crumble (ibid).

Hence, it is within these seditious stories that the potential for resistance lies. As bell hooks (1995) contends, 'oppressed people resist by identifying themselves as subjects, by defining their reality, shaping their new identity, naming their history, telling their story' (as quoted in Plummer 1995: 30). Conversely, narratives which exemplify the status quo provide detailed explications of the nature and the power of the norm.

In concluding this discussion on the addition of the phenomenological to the poststructural, it is vital to reinforce the fundamental significance of my belief that the personal is always embedded in a social framework. According to this way of thinking, the personal is never a singular, isolated experience, and, therefore, it is representative, like any text, of the social, political and historical conditions which have created it. This is why personal narratives contain so much power to reveal sociological insights. As Stanley (1993) argues, ‘from one person we can recover social processes and social structure, networks, social change and so forth, for people are located in a social and cultural environment which constructs and shapes not only what we see but also how we see it’ (italics original) (45). When seen in this light, personal narratives can be appreciated as so much more than the ‘true confessions’ that Barnes (1998b) believes should be excised from disability studies, they are political accounts which can be drawn on to both illuminate and emancipate.

The narratives which form the backbone of the thesis stem from a variety of data sources, including my dialogues with participants, written stories from participants, and published autobiographies. Their analysis results in the emergence of the following themes: independence, occupational identity, and sexuality/appearance. Each theme is discussed in a separate chapter, from Chapters Five to Eight, and attempts to let the stories speak for themselves by way of lengthy excerpts from the participants and texts, and combines them, where relevant, with my own insights and experiences as a disabled person.
Governmentality is both a concept and a tool of analysis. As a concept it describes the ways in which our most personal thoughts and deeds are connected to a diffuse system of power relations mediated by discourse, and as an analytical tool it is capable of contextualising our everyday experiences within a governmental framework. Through governmentality, Foucault challenges political science's desire to encapsulate the workings of power in a "theory of the state" which views power as 'a centralised locus of rule' (O'Malley et al. 1997: 502). Indeed, Kerr (1999) argues that 'he refrained from a theory of the state in the sense that one abstains from an indigestible meal' (175). What is so important about this departure from conventional notions of power is that it breaks down the dichotomy between the public and the private, the political and the personal, and acknowledges that the most appropriate site of political analysis exists 'within the encounters that make up the everyday experience of individuals' (Rose 1996b: 37).

Within a conventional political analysis, disability would be viewed as a medical problem which is mediated by political programmes that allocate funds for pensions, social services, and medical treatment. Critique within this analysis would focus on any blocks in the flow of service delivery predicated by changes in political policy. Conversely, Foucault's notion of "government" enjoys much wider connotations and is understood to be not simply the workings of political institutions, but in a broader sense as 'the conduct of conduct: a form of activity aiming to shape, guide or affect the conduct of some person or persons' (Gordon, 1991: 2). Government, thus, does not reside in the halls of power which mete out favours or punishments, it exists as 'a contact point between technologies of the self (self-subjection) and technologies of domination (societal regulation)' (Petersen 1997: 202-3).

From this understanding of government, Foucault (1991h) devised the neologism governmentality from the union of "government" and "mentality". Governmentality, Rose (1996b) explains, is 'a kind of intellectual machinery or apparatus for rendering reality thinkable in such a way that it is amenable to political programming' (42). Genealogy gives us a firm grounding in how these ways of thinking are developed via the intellectual mechanisms of liberal philosophy and positivist science, and the notion of governmentality take us one step further by demonstrating how these mentalities become immersed in contemporary regimes of power.

Governmentality studies attempt to make sense of the development and operation of the ways in which populations are rendered thinkable and measurable for the purposes of government. They focus on the 'mentalities' of rule, understood as the self-scrutinising intellectual linkages forged between abstract political rationalities and the strategies and technologies through which they are implemented (Stenson 1998: 333).

When viewed as a function of governmentality, disability can be seen a concept which justifies surveillance and intervention, and, even more importantly, it forms a conceptual distinction
between those who can and those who cannot fully participate in political life. In consequence, those who are found lacking according to the definitions devised within existing mentalities of rule become subject to a series of technological interventions which serve to exemplify which qualities are to be sought after in late modern liberal democratic societies.

The dominant mentality of rule which informs the mechanisms of government in contemporary Western democracies is neoliberalism, a political rationality which ‘has emerged over the past two decades from a union of classical liberal thought and a new set of ideals which are relevant to an increasingly individuated society based on autonomy, choice and economic primacy’ (Galvin 2002: 118). Rose (1992) argues that ‘neoliberalism is more than a phenomenon at the level of political philosophy. It constitutes our mentalities of government, the conception of how authorities should use their powers in order to improve national well-being, the ends they should seek, the evils they should avoid, the means they should use and, crucially, the nature of the persons upon whom they must act’ (italics mine) (145). Disability, as a category of government, has been reconstituted as an identity which is antithetical to the attributes of the ideal neoliberal citizen. Those who are defined, or taken for granted, as able-bodied are believed to be capable of achieving such lifestyle goals as wealth, independence, health, fitness, employment, market participation, and a range of leisure pursuits which help to define their individuality. Conversely, those who are disabled are seen to be so because they are defined in relation to their lack in these areas of achievement.

Governmentality thus provides the ideal framework through which to understand and challenge the construction of the disabled identity in contemporary times. Because governmentality studies have been ‘designed to form a mid-range explanatory level between the history of political philosophy and an empirical study of social relations’, they are firmly grounded in ‘the nexus between everyday practices ...and more abstract technologies and broader political rationalities’ so they avoid ‘the political insulation characteristic of many micro-focused frameworks’ (O’Malley et al. 1997: 505, 503). However, although this methodological melding of the political and the personal, ‘the totalising and the individualising’ (Gordon 1991: 36), forms an analytical mechanism which should be conducive to the questioning of governmental practices which privilege some identities at the expense of others, governmentality studies have largely been confined ‘to gestures of formal support for political contestation’ and have demonstrated ‘a lack of interest in transferring knowledge beyond the limits of academic audiences’ (O’Malley et al. 1997: 503, 504) and, thus, they have not been engaging in the kind of emancipatory work I believe them to be capable of informing.

Gane and Johnson (1993) note that the genealogical project ‘seems after Foucault’s death to have become detached from its original and practical matrix and to have become, perhaps inevitably, abstract and academic’ (7). I believe, in keeping with my methodological stance, that this is largely due to the fact that these studies have distanced themselves from the voices of
the very people whose governance they seek to analyse. O'Malley et al. (1997) argue that, because of 'its emphasis on the programmatic nature of rule', the governmentality literature emphasises the analysis of texts at the expense of what they refer to as 'the messy actualities' of governance (503). This results, Weir (1996) argues in the erasure of 'counter discourses' and a subsequent severing of the 'relation [of genealogies] to subjugated knowledges' (388). This, I argue, is a fundamental problem with any form of analysis which retains a "top-down" approach. Kerr (1999) states that 'while this work addresses important issues, it does so in a way that limits its critical and emancipatory potential. Governmentality is seen to be based on a "top-down" and dualist conception of power, one that externalises and marginalises contradiction and struggle to become a theory of social reproduction rather than of transcendence' (179).

O'Malley et al. (1997) suggest that this separation of political analysis from the lived experience of the people it is directed towards may have been reinforced by Foucault's earlier distinction between 'serious statements' and 'everyday discourses' in his "archaeological" work (512). They argue, however, that to ignore everyday language and experiences is to deny governmentality studies their potential to feed into liberatory strategies because '[r]esistance is a form of social antagonism that commonly occurs at the boundary between serious statements and everyday statements' (ibid). Therefore, they consider it essential that 'a broader range of social institutions and actors needs to be accepted as sources' (ibid). Stenson (1998) concurs with this view and argues against the 'narrow focus on texts' within the governmentality literature, which, furthermore, is based, he believes, on the depiction of mentalities of rule 'as tidy, univocal constructions, at the expense of analysing the complexity of voices and interplay between talk and text in political discourse and practices' (334).

My methodological framework has been specifically designed to overcome these problems. I envisage that the personal narratives, which are to be analysed during the qualitative stage of my research, will perform their role as cultural texts which will complement the host of other texts drawn upon during the governmentality phase. I believe that the abstract nature of the governmentality literature and its suspicion of empirical research have not existed as epistemological necessities. Rather, they have performed an important yet short-term role in the development of poststructural analytics in which the need to reinforce its distance from both the creation of absolutes and the fixity and essentialism of the liberal individualist subject has been required to remain uppermost while a new framework could be developed which would be capable of contesting social injustice without falling back into modernist assumptions. What I hope to achieve in using governmentality to locate the inner experience of individuals in its social and political context is an innovative response to Stenson's (1998) call for the dismantling of the 'boundaries between the study of the intellectual dimensions of [governmental] phenomena and the study of the messiness of human practices' (350).
Within Chapters Nine to Eleven, I use a governmentality analysis to explore the core categories and to place them in their current social and historical context. Here I suggest that independence, work and sexuality are key factors which are used to divide the affiliated from the marginalised in contemporary neoliberal societies. I argue that the two “technologies” which currently have the most impact on how independence, work and sexuality are governed in relation to disability are welfare reform and sexual rehabilitation. In Chapters Nine and Ten, I explore the available primary sources - particularly the last five years of Australian government policy on welfare reform and a selection of sexual rehabilitation texts - to reveal how governance seeks to operate as a liberatory force while remaining oppressive due to its paternalism and reinforcement of normative prescriptions. Chapter Eleven further problematises disability in relation to the governmental concepts of “self-esteem” and “empowerment” in an attempt to unpick what can be claimed to be emancipatory from what remains embedded in the dominant discourse. Ultimately, by bringing to the surface the mechanisms for the construction of the disabled identity and the intricate connections between power and subjectivity, I aim to demonstrate that agency is possible.

Toward an Effective Emancipatory Research Model

I propose that the methodology I have just outlined allows us to move one step closer to achieving the emancipatory ideals of disability research because it builds a link between theory and practice which has the potential of bringing poststructural analysis out of the academy and into the "messy actualities" of human existence without sacrificing its theoretical rigour. I argue that this approach avoids the problems of both "top-down" approaches, which ignore the political nature of personal life, and "bottom-up" approaches, which remain trapped within the hegemonic paradigms they strive to break free from, because it is representative of a coalition based on reciprocity where both the "top-down" and "bottom-up" elements can usefully coexist. To achieve this union requires that the theoretical and practical elements continually feed into one other. In other words, it is vital that the voices which are raised during the qualitative component are used to inform the academic analysis, and, conversely, that the theoretical insights which are developed via the process of critical analysis are made accessible to the subjects of the research (both the participants and the general group being focused upon, in this case, disabled people) so that they can make use of them in improving their lives.

I originally viewed genealogy as a distinct approach which I sought to combine with grounded theory in the hope of providing the narratives with a critical historical framework which would allow for the problematisation of the central conceptual components of my research. It is certainly true that genealogy does in fact perform this function, but I have come to see that genealogy is more than that. It is a way of seeing things and exploring them, and, through this vision and this mode of investigation, it overarches all of my work in such a way that I have come to think of my methodology in terms of "grounded genealogy". By grounding genealogy in
local knowledges as well as drawing from academic critique, I hope to demonstrate that it is possible to avoid such prescriptions and modernist assumptions, while bringing critical analysis in touch with the people it is attempting to better understand and, ultimately, to liberate. I believe that emancipation becomes possible when theory both draws from and informs lived experience, in other words, when it becomes grounded in real life.

A genealogical approach to disability research does not offer yet another methodology which promises to deliver a more accurate set of "truths" than the medical and social science models which have gone before. Instead, it provides a critique of the very assumptions upon which these forms of "scientific" research rest. Therefore, what emerges is the recognition that it was not merely the kinds of "truths" that these research models offered which were in error. The problem lay rather in their belief that they could offer singular, universal truths at all. Historicising the evolution of the medical and social sciences unseats the dominant view that they are objective, value-neutral mechanisms for determining the "truth". Instead, what we see is that science is based on a system of values which personalises and essentialises what are actually social problems, and, by demonstrating that what has been claimed to be scientific knowledge is actually just one of many possible interpretations based on certain assumptions, a genealogical perspective can pave the way for other interpretations which do not claim to be more accurate, simply that they remain open to the questioning of their own assumptions.

The basic aims of emancipatory research are to challenge the oppressive features of existing research into disability and to prioritise the needs and interests of disabled people. It should be clear by now that much existing research on disability has been inherently oppressive because it has not acknowledged the social causes of disability. However, some of the research which has focused on deriving data from disabled people has been oppressive in much more serious ways and is being referred to in terms of a 'rape model of research' because it is 'alienating, and disempowers and disenfranchises disabled research participants by placing their knowledge into the hands of the researcher to interpret and make recommendations on their behalf' and 'that researchers are compounding the oppression of disabled respondents through exploitation for academic gain' (Kitchin 2000: 26). A classic example of this kind of research was perpetrated by Miller and Gwyne (1972) when they attempted to analyse the situation of disabled people in institutions. They concluded, Finklestein (1998) states, 'that the function of the residential institution was to provide the "socially dead" with transitional care until natural death occurred' (38). Research which studies disability from a mainstream social science perspective may not be as overtly discriminatory as Miller and Gwynne's, yet, there is still a great deal which can be considered 'intrusive and disempowering ...and which serves the damaging and oppressive purposes of a service system over which [disabled people] can exert little or no influence or control' (Beresford 1999: 3).
Disability researchers maintain that the most important features of emancipatory research are that it prioritises the needs and well-being of its participants (Gibbs 1999; Goodley and Moore 2000), that it listens to and respects the voices of disabled people (Barton 1996; Gilson, Tusler and Gill 1997; Moore et al. 1998), and that it aims to raise the status of disabled people in general (Anspach 1979;; Couzer 1997; Barnes, Mercer and Shakespeare 1999). When Kitchen (2000) asked disabled people about their preferences for research techniques, there was 'strong support for qualitative methods of research, particularly interviews because they allow respondents to express and contextualise their true feelings, rather than having them pigeon-hold [sic] into boxes with no or little opportunity for contextual explanation' (43). Carspecken and Apple (1992) also add that what they refer to as 'diadigmatic data generation' allows the participants some 'control over the research process, yielding a more democratic form of knowledge production' and they conclude that:

dialogical methods are empowering to the groups being studied. Sensitive questioning can often help people articulate features of their culture, and their feelings, for the very first-time. Since articulating formerly tacit conditions helps one to distance one's identity from the structures within which it is frequently embedded, this method can be empowering to the subjects of study, and it can change the ways in which they routinely act (531).

This kind of distancing from hegemonic discourses involves a very similar technique to that which was basic to the development of "consciousness raising" by second wave feminists in the 1970s, involving the gradual process of group identification and the articulation of shared problems.

I believe that it is also possible to generate this kind of consciousness raising process through research which is based on dialogue between disabled people because the narratives which emerge are usually built on the realisation that their problems are not the result of individual aberration but of shared oppression. I quote Haber (1994) here at length because what she has to say about this process reflects exactly what I believe it is possible to achieve through emancipatory research based on the sharing of stories.

The recognition of similarity with others is crucial in denying and recognising the harmful political implications of the public/private split. It is the recognition of the similarity of my pain or oppression in someone else that allows me to deny the idiosyncratic nature of my experience, and to deny my guilt at being different from the "norm." Coming to this recognition, identifying a "personal" pain with a pain belonging to others, and the consequent recognition of the ideological nature of these pains, is what makes [certain emancipatory] novels... so effective in voicing marginalised identities, raising consciousnesses, and galvanising opposition. The recognition of similarity and the possibility of solidarity wakes us from the stupefaction of normalising and disciplinary
discourse. The fact that such similarities and solidarities are partial and perhaps temporary does not lessen their fundamental importance (133).

In acknowledging the momentary and partial nature of these similarities we break down one of the walls which has kept poststructural analysis separate from qualitative research techniques. It is not necessary nor is it desirable to claim that, in sharing our narratives, we will come up with one superior master narrative which will name the oppressor and solve everything. What we can aim for, however, is the opening up of a space where a multitude of counter-narratives can be developed, listened to, and respected.

In concluding this chapter, I would like to reiterate that my prime objective in developing the methodological framework I have outlined herein is to attempt to devise an emancipatory research model which is capable of utilising theory and practice in a reciprocal manner. Throughout my discussion I have attempted to address the many arguments which have conventionally been drawn upon to keep these areas clearly separated, but I have not, as yet, outlined the very personal choices upon which this methodological merger relies. Three points are of particular relevance here. Firstly, I take a subjective stance in my work, acknowledging that my beliefs, values, objectives, and personal experiences have an enormous influence on the way I choose to approach my research and how I will interpret what I discover during the process. Secondly, and closely related to this, is the fact that I am disabled, something which I believe puts me in a much stronger position to select and interpret issues which are of value to other disabled people. And, finally, I believe it is vital that I attempt to make my work accessible to disabled people, specifically to my participants, but, in general, to anyone who identifies themselves as disabled and is looking for ways to escape their marginalised status.

When I attempted my first, major academic treatise, I only mentioned my own situation briefly and felt extremely uncomfortable about doing so. I still find it difficult because all of my training, up until recently, has demanded that I divorce myself from the topic of study and become an objective observer. However, the logic of my own methodological position means that it is not only vital that I acknowledge how my subjective stance will affect my research, it would be absurd, as well as hugely inconsistent, to pretend that I am capable of being anything other than subjective. In keeping with this recognition, Aldridge (1993) criticises what she refers to as ‘the simplistic epistemological ideas assumed’ in such positivistic frameworks which ‘actually hinge on complex writing conventions that “textually disembodify” the knowledge contained from its time, place and person of production’ (54). Ribbens (1996) describes these conventions as ‘linguistic disappearing acts’ based on a ‘hollow … claim to objectivity’ (81) and Plummer (1983), one of the first sociologists to argue for the reintroduction of a subjective approach, proposes that the objectivist stance which has come to be expected results in ‘research reports [which] have often been written as if they have been executed by machines’ (57). In contrast, Glaser and Strauss (1967) refer to the personal experiences of the researcher as ‘experiential
data’ and argue that ‘it should not be ignored due to the usual canons governing research (which regard personal experience and data as likely to bias the research), for these canons lead to the squashing of valuable experiential data. We say, rather, "mine your experience, there is potential gold there!"’ (11).

It is becoming more common for disability theorists to locate themselves within their research and to specify how this affects their position. Shakespeare (1996), in discussing his approach to disability research, makes it clear that he is firmly committed to working towards positive change in the lives of disabled people. He declares, ‘I support the cause of disability rights, I support the principle of self organisation and I support the disability movement. This is an ethical or political position which informs everything I do, professionally and personally. I think it is clear from my published work that I am not a disinterested observer, but a participant in the process I describe’ (117). I wish to take this one step further through drawing on my own autobiographical writing during the grounded theory phase of my research. In this sense I will be participating simultaneously, or alternately, as researcher and researched. I find the idea to be extremely intimidating, but I strongly believe that my own story will help to illuminate the areas I wish to analyse and my willingness to tell it should make clear that I am prepared to renounce the last vestiges of my belief in the necessity, indeed the possibility, of attaining an objective stance.

To do so, however, is not without its problems. For, although the use of ‘systematic autobiography’ can be traced back as far as Cooley and can also be found in the writings of C. Wright Mills, Goudner and Berger (as discussed by Ribbens 1996: 87), it can nevertheless be argued that the practice of including subjective descriptions and/or autobiographical material is self-indulgent (Cotterill & Letherby 1993; Ribbens 1996), interferes with sociology’s fundamental focus on the collective (Evans 1993), makes criticism difficult (Cotterill & Letherby 1993), and/or leads to the production of ‘lifeless character sketches’ or ‘guilt-ridden, scab-picking, self-explorations’ (Brandt et al. 2001: 46).

Against this, those who subscribe to autobiographical positioning and inclusions argue for their articulation within a strong theoretical framework. The techniques for achieving this particular form of marriage between theory and practice have been described variously as ‘intellectual autobiography’ (Stanley 1990: 120), ‘personal criticism’ (Miller 1991: 1), ‘interpretive and analytic autobiography’ (Aldridge 1993: 55), and, more generally, ‘systematic autobiography’ (Goodwin 1973: 27). Although Aldridge (1993) believes that this should not involve ‘the issuing of personal data along with the writing up of the research’, in my case, it will. As my process of data generation is dialogical and because my personal experience with disability has been impacted upon so intensely by my theoretical engagement (and vice versa), my voice and my experiences will be brought to the surface where relevant. I believe, in keeping with Callan (1984), that the social nature of the personal can be drawn out in theoretically relevant and
rigorous ways by engaging in a ‘disciplined monitoring’ of individual experience (as quoted by Ribbens 1996: 87).

Stemming from the consideration of my subjective position, I feel it is vital to acknowledge the role that being disabled plays in my research. There is currently a debate going on within disability studies as to whether non-disabled researchers should be allowed to conduct disability research at all (Bricher 2000). I do not agree that excluding non-disabled researchers is advisable, but I do suspect that disabled researchers may be better equipped to conduct qualitative research projects which aim for emancipatory outcomes. Kitchin (2000) interviewed a range of disabled people in relation to their research experiences and many of her participants reported that they felt that non-disabled people ‘potentially misrepresent and misinterpret disabled people’s experiences and knowledge because they themselves have never experienced what it is like to be disabled’ (33) and that ‘disabled people will only tell partial stories to a non-disabled researcher for fear of embarrassment or lack of empathy’ (34). In the case of my own research, I have found that my participants are excited about its potential and that we are building a relationship based on empathy and shared experience rather than one of the all-knowing researcher and the passive object of research. And, as I discussed earlier, dialogue between disabled people can result in a consciousness raising process which can facilitate the healing of damaged identities.

Finally, I reiterate that my research will have little chance of being emancipatory in any kind of practical sense if it is not made accessible to the people it focuses on. I recognise that the development of theory is a vital element in challenging oppression and that the insights which emerge from theory have the potential to enter the systems of knowledge which inform emancipatory movements. However, it seems to me that much of this vital information is kept locked in a form that is only accessible to an elite few and that the same notions of "trickle down" that are used to justify economic rationalism are assumed to join theory to practice within the social sciences. Thus, I am in complete agreement with Germon (1998) when she argues that ‘[i]t is contradictory to promote empowerment and emancipatory approaches when the findings are inevitably inaccessible to an audience of disabled activists’ (251) and, I would add, to disabled people in general.

Moore et al. (1998) discuss the importance of aiming research at the needs of disabled people and presenting it in ways that are accessible to them. They made a choice which favoured maximising the relevance of their research for disabled people at the expense of maintaining the standards required for publication in refereed academic journals. I applaud them for their decision to remain true to their participants. However, I have attempted to devise a means of being able to present the findings of my research to both an academic and a non-academic audience by using two formats in my writing. As well as my dissertation and the academic publications which are drawn from it, I intend to prepare two documents which will be aimed at
sharing my research with a non-academic audience. I have notified my participants that I will be sending them a report which translates the results of my theoretical analysis into more accessible language and that, additionally, I will be writing a book which will use their stories to provide insights to disabled people in general. Transforming my academic work into everyday language is a skill I am keen to develop because I believe that my work will be of greatly reduced value if it cannot be fed back into the lives it is based upon.

More generally I believe this kind of critical research has the potential to provide emancipatory insights to a larger audience than that represented by disabled people, for it is not only they who are disadvantaged by the dividing practices which separate the desired "norm" from the undesirable deviation from it. As will be discussed in the following chapter, the norm is such a pervasive and virtually impossible standard to fully attain that it has become a trap within which all people who strive to become "good citizens" are caught. Disabled people may well suffer from inferior social locations because of their perceived incapacities, but for those who struggle to maintain their normality, the constant state of guilt, worry and uncertainty over such things as which foods to eat, how much exercise to do, how to parent effectively, and how to develop good self-esteem derives from the same logics which serve to police the boundaries between the affiliated and the marginalised (Harris 1994). The fear associated with becoming one of "them", one of the unacceptably different, is, I believe, a more powerful force for shaping human behaviour and, consequently, denying people any sense of real freedom, than the most autocratic form of government.
PART TWO

Genealogy
CHAPTER TWO

The Fractured Collage of Disability

There is no history of thought outside the history of systems of thought. There is no speech outside systems of languages. . . There is no disability, no disabled, outside precise social and cultural constructions; there is no attitude toward disability outside a series of societal references and constructs. Disability has not always been seen in the same way (Stiker 1999: 14).

[It was] constituted by all that was said, in all the statements that named it, divided up, described it, explained it, traced its development, indicated its various correlations, judged it, and possibly gave it speech by articulating, in its name, discourses that were to be taken as its own (Foucault 1972: 32).

There can be no doubt that bodies denied of perfect function have always existed, bodies which lurch or move unbidden or not at all, twisted bodies, broken bodies, bodies whose physical differences have exceeded acceptable limits. In contemporary times we have devised a category which we have named "disability" to describe such bodies and in this chapter I discuss the origins of this process of naming. The roots of disability as currently defined are difficult to tease out as they do not radiate from a common point of origin. Rather they are tangled, broken, elusive and illusionary. Conventional histories do not recognise the seismic ruptures that have carved gaping fault lines in the landscape from which humanity has continued to erupt, as these histories are built on the assumption that the contemporary concepts they seek to trace have always existed and have developed in an unbroken form and in an evolutionary fashion. When applied to disability this approach would have us believe that disability as we know it has always been recognised as a culturally relevant category and that modernity has introduced progressive elements which have gradually improved the conditions under which disabled people live. A genealogical approach, however, reveals a vastly different conceptual trajectory because it is capable of demonstrating the contingent and fractured heritage of the social construction of disability.

The historical rupture which created the conditions for the emergence of disability as we now know it was riven by the massive upheaval that spanned the eighteenth and nineteenth centuries in Western societies. During this time monarchies fell one after another and were replaced by the huge, sprawling bureaucratic network of the modern administrative state; industrialisation swept the countryside drawing into its vortex the rural peasantry and, leaving in its wake, charred, smoke filled cities built on, for and by the human cogs essential to the functioning of the new machinery of capitalist production; and a whole new way of thinking about people, how they should see themselves and shape their lives was made possible by the
development of liberal philosophy and positivist science. It was during this time that disability became a category which both reflected and was vital for the creation of the ideas, processes, strategies and techniques that have evolved into our current modes of "government" in a Foucaultian sense. Disability became administrative, medicalised, institutionalised, calibrated, and ontologically vital for the definition of the modern subject. It became a tool to be deployed which not only affected those who were defined within its bounds, but which has impacted on all people as a measure of their compliance to cultural conventions.

Davis touches on this time of rupture when he argues that '[a]lthough there may have been a great number of people with disabilities, one must, however, assume that disability was not an operative category before the eighteenth century' (Davis 2000 57). Indeed, historians have a great deal of difficulty in documenting disability before this time as it is not referred to in the same way and sometimes seems to escape mention at all.

Obviously this is not because persons with disabilities were lacking. Indeed, it is probable that the figure of 15 percent, now generally accepted as the percentage of people with disabilities in the United States and throughout the world, would have held in the past. In fact we might estimate upward of 25 percent of the population was disabled, given the lack of modern medicine and so on (ibid).

It is here that etymology can assist the critical historian. The Oxford English Dictionary shows that the word "disability" was used in a very different way prior to industrialisation. For example, in 1580, Lupton refers to 'his disabilitie to perform his promise' which is a usage more akin to our general term of in-ability. The same applies to Milton's reference in 1645 to 'disabilities to perform what was covenanted'. In these two cases the word may still refer to an inability to perform a certain function but it is not being linked to physical impairment. It would seem that anyone could be disabled now and then, depending on the circumstances. It is not until well into the eighteenth century that we see references to disability which reflect its contemporary form. In 1768 Tucker writes of 'inconveniences, disabilities, pains, and mental disorders' which places it in a much more familiar setting, and when Anderson in 1870 uses the phrase 'crippled by the disability' it is clear that he is referring to the kind of functional impediment which currently circumscribes our notions of disability (italics mine).

However, the question remains that, if disability as a case of functional impairment existed, as it surely must have, prior to its current conceptualisation, what words were used to describe it and how was it perceived? Davis (2000) argues that '[r]ather than disability, what is called to readers' attention before the eighteenth century is deformity. The word seems to have been in use since the beginning of print, according to the Oxford English Dictionary, and is the operative word in defining some aspects of physical disability' (58). According to this perspective, prior to the eighteenth century, what achieved attention as a negative distinguishing feature had more to do with appearance than function. Even so, Davis (2000) demonstrates that deformity and
other forms of physical difference which would now be classed as disabilities seemed to blend into society and be granted a greater level of acceptance in the centuries preceding the 1700s.

Samuel Johnson (1709-1784) provides a particularly vivid example of Davis's point that disability was largely ignored in earlier times. Johnson, a celebrated author, had multiple disabilities, which, if he had lived in the twentieth century would have resulted in institutionalisation, discrimination and pathologisation. He was almost blind, partially deaf, was severely scarred by small pox and evinced the behaviour now referred to as Tourette Syndrome, yet his contemporaries saw him 'as a brilliant man who had some oddities rather than as a seriously disabled person' (Davis 2000 55). Davis argues that this casual view of Johnson's disabilities is representative of the liminal period in which he lived where 'we can see the contradiction of an earlier sense in which disability per se did not exist and a latter one in which disability is a modality used to explain a great deal' (56). While his disabilities were not completely ignored, neither were they thought to be of any great importance.

However, the liminal period reflected in Johnson's experience was soon to draw to a close and disability was to become a mode of classification which heralded not only a whole new way of viewing physical difference, but a revolution in the largest sense possible in relation to what could be thought, said and done. In suggesting that disability took on a certain shape due to the interplay of capitalism, industrialisation, and liberalism, the rise of medicine and other forms of expertise, and the creation and consolidation of administrative government, I am not overlooking that it has been deployed in the service of varying, sometimes conflicting, interests over this time. What I will be attempting to demonstrate, however, is that these interests have been formed within a system of rationalities and technologies which have been constitutive of what we have come to classify as modernity where disability has been come to be understood as the inferior side of a dichotomy which casts "able-bodiedness" as the norm.

The Imperative of Labour

The ruptures and fragmentary connections from which the category of disability originally grew were most clearly linked to the conditions surrounding the mechanisation of labour and the ways in which these came to interact with systems of governance. Industrialisation tended to undermine traditional kinship ties and community support structures because of the social dislocation, rapid urbanisation and increasing geographic mobility which ensued, and, alongside and in keeping with the advent of the modern workforce, a whole new range of disciplinary mechanisms came into play. Foucault argues throughout his genealogical work that this mode of discipline was grounded in a growing surveillance of the population and an accompanying redistribution of individuals in space. Fundamental to this change in the operation of power, he maintains, was the development of 'dividing practices' whose primary purpose was to cleave a
dichotomy, both physical and symbolic, between those who could and those who could not respond favourably to the 'imperative of labour' (Foucault 1991b: 128).

Proponents of the social model argue that, prior to industrialisation and the demands of factory production, it was possible for people who had a range of functional and sensory impairments to engage in productive activities because their differences could be accommodated and their skills utilised (Barnes, Mercer and Shakespeare 1999; Linton 1998; Oliver 1990). This allowed them to blend into their communities and, as such, '[d]isabled people did not constitute a socially recognised group' (Patterson and Hughes 2000: 36). However, with the onset of large scale factory production, came the requirement for workers to fit the mold stamped out by mechanisation and the timetable, and this put people who lacked the qualities necessary for this kind of labour at a distinct disadvantage. As Marks (1999) argues, '[m]echanised production required a uniform workforce . . . and work was not organised to cater for the range of intellectual and bodily differences between people' (80). “Disabled” thereafter became the term used to describe those who could not perform in accordance with the demands of the modern labour force.

Obviously work has always been an important factor in defining people's lives and ensuring their survival. The difference in the modern era is that work has taken on a new shape and become immersed in a particular ideological framework and regime of disciplinary mechanisms. Foucault (1980a) argues that, while work has always had a productive function, in the modern era it has taken on two additional functions, 'the symbolic function and the function of *dressage*, or discipline' (161). Those who could not participate in this new social realm could only be seen to be lacking the symbolic and disciplinary qualities of the autonomous, rational, market-driven liberal subject and thus were defined as aberrant. As Jolly (2000) argues, '[t]he administrative categories of "able to work" and "unable to work" [were developed] to identify those who because they did not, or could not, participate in the central system of work were a threat to the social order. In short, those who did not work for whatever reason were a social problem' (796).

This dichotomous formation of the "able to work" and the "unable to work" resulted in those from the latter category being reduced to poverty and forced into a life of mendicancy because their former means of survival had been lost in the social transition. The fear and distaste that this destitution caused the growing middle class is reflected in the amendments to the Poor Laws of England in 1834 which, by withholding relief outside of institutions, ignited the process of segregation which, by physically removing disabled people from sight, served to reify the social exclusion that had already been constructed around their new categorisation (Winzer 1997: 98-99). Originally the poor, the sick and the disabled were rounded up and housed in leprosaria which had been abandoned due to the decline in leprosy (Foucault 1973), but their numbers grew so rapidly - Barnes et al. (1999) estimate that in Britain '[t]he [general] asylum population rose from three per ten thousand at the beginning of the nineteenth century to thirty per
thousand at its end’ (19-20) - that the building of new institutions became an industry of its own over the next two centuries.

The purpose of this process of exclusion, which Foucault (1991b) calls the ‘great confinement’, was not simply a matter of ridding the streets of poor people or of providing care to those who needed it. It was, he argues, a ‘dividing practice’ whose primary purpose was to ‘revis[e] the distinctions between the affiliated and the marginalised’ (Rose 1996c: 340) and to ensure that ‘the subject [was] objectified by a process of division either within himself or from others’ (Foucault 1982: 208). As such, a key purpose in creating the category of disability has been to provide a clear demonstration of what not to be and, accordingly, as Davis (1998) suggests in relation to the confinement of disabled people in early modernity, ‘as a deterrent to the able-bodied’ (1).

While the institutionalisation of disabled people from the eighteenth century onwards was ostensibly geared at providing relief for those who could not work, confinement was not, in reality, designed for compassionate reasons. As Foucault (1991b) argues, ‘[w]hat made it necessary was an imperative of labour … Our philanthropy prefers to recognise the signs of a benevolence toward sickness where there was only a condemnation of idleness’ (128). Hence, as Davis (1998) points out, by the time ‘the Poor Law was amended in 1834, the majority of workhouse inmates were in fact… the physically and mentally disabled, the aged, the orphan and a wide variety of sick’ (1). One such institution in France bore a plaque on which was written: ‘If wild beasts can be broken to the yoke, it must not be despaired of correcting the man who has strayed’ (quoted in Foucault 1991b: 139). Unable conform to the moral imperative implicit in the modern configuration of labour, centred as it was around the tyranny of the timetable and the excision of any opportunity to disrupt the rhythms of the productive process, the disabled body could not be disciplined and was thus relegated to life on the margins of society.

Foucault (1977c) argues that the rationalities surrounding institutionalisation rested on a combination of principles which had sprung from the differing historical measures designed for the treatment of lepers and plague victims. ‘If it is true that the leper gave rise to rituals of exclusion, which to a certain extent provided the model for and general form of the great confinement, then the plague gave rise to disciplinary projects’ (198). According to this logic, the disabled person was marked as inferior and excluded in the same way as the leper of the middle ages, but the rise of the institution also reflected a way of controlling bodies in space that had been inspired by the conditions of the great plagues and which relied on surveillance, observation, individuation and training. It was this combination of exclusion and discipline which formed the ideological basis for what was to become the single most defining feature of the construction and oppression of the disabled, the ‘hegemony of normalcy’ (Davis 1997a: 23).
The Hegemony of the Norm

The constant division between the normal and the abnormal, to which every individual is subjected...[applied] the binary branding and exile of the leper to quite different objects; the existence of a whole set of techniques and institutions for measuring, supervising and correcting the abnormal brings into play the disciplinary mechanisms to which the fear of the plague gave rise. All the mechanisms of power which, even today, are dispersed around the abnormal individual, to brand him and to alter him, are composed of those two forms from which they distantly derive (Foucault 1977c: 199).

That disability is considered to exist in opposition to some kind of more privileged state is apparent in its linguistic structure. *Dis*-ability, *mal*-formation, *de*-bility, *im*-pairment, *in*-valid, *de*-formed, *dis*-figured. 'All these words, curiously negative (negating what?), evoke a fear' (Stiker 1999: 4). In posing the question, 'negating what?' Stiker points to the way that disability has been constructed as "the other" in a dualistic category which is set against the "the norm". So, then, what is this "norm" and why does disability fall foul of it?

In his etymological analysis, Davis (1997a) explores the history of 'the constellation of words describing [the] concept "normal," "normalcy," "normality," "norm," "average," "abnormal"' (10). The word "normal" only appeared in the English language in 1840 in its current form, where it is defined as 'constituting, conforming to, not deviating or different from, the common type or standard, regular, usual'. Prior to that it meant 'perpendicular'. Similarly, 'the word "norm," in the modern sense, has only been in use since around 1855, and "normality" and "normalcy" appeared in 1849 and 1857, respectively' (ibid). The entry of the concept of the norm into the English language at this stage reflects a way of thinking and a means for controlling bodies which had been developing for almost a century. 'Like surveillance and with it, normalisation becomes one of the great instruments of power at the end of the classical age' (Foucault 1977c: 184).

This insertion into language of what had already been developing as a concept was made possible by the emergence of the field known as statistics. Statistics was to provide a system of measurement which was to link the inculcation of values with the supposedly objective, value-neutral mechanisms of the evolving human sciences (Hacking 1991). The ability to quantify the division between what was desirable and what was not, proved to be a potent tool in the administration of populations. It was the French statistician Adolphe Quetelet (1796-1847) who managed to solidify the norm by linking it to the bell curve, the graph which shows the "normal distribution", the majority and its margins, of any population. When Baynton (2001) discusses the nature of this majority, he points out that '[a]lthough normality ostensibly denoted the average, the usual, and the ordinary, in actual usage it functioned as an ideal and excluded only those defined as below average' (36). It was in this way that the rising arch of the curve seemed to, paradoxically, denote the superiority of the unexceptional.
Davis (1997a) argues that, prior to the construction of the norm, there was the “ideal”. For example, in classical culture there existed the concept of the ideal body which was symbolised in painting and sculpture. The difference between the ideal and the norm is that, while people may greatly admire the ideal, nobody is expected to achieve such standards of perfection. Everyone necessarily falls short of the ideal. Conversely, the idea of the norm is the standard to which everyone is expected to conform and anyone who falls outside its precincts is considered to be deviant. In this way, the norm becomes a much more tyrannical concept than the ideal and, in fact, becomes a new kind of ideal, one which, unlike its classical forebear, is thought to be within reach of most people (Davis 1997a: 11). As Quetelet wrote, ‘an individual who epitomised in himself, at a given time, all the qualities of the average man, would represent at once all the greatness, beauty and goodness of that being’ (quoted in Davis 1997a: 12).

Disability is obviously antithetical to the norm on a great many levels. Those who are disabled often fall short of the norm in relation to the characteristics of appearance, strength, mobility, wealth, and independence and this has resulted in their symbolic as well as their physical exclusion from mainstream society. In the latter part of the twentieth century these departures from the norm lay at the heart of the eugenics movement. Here, Davis (1997a) draws our attention to the macabre ‘coincidence’ that the most prominent statisticians of the nineteenth century were also leading lights in the eugenics movement. Put simply, these people believed that the ultimate form of normalisation was in ridding the population of its defectives (18).

Francis Galton, a cousin of Charles Darwin, introduced the term eugenics in 1883 as ‘the science which deals with all influences that improve the inborn qualities of a race’ (Cocks and Stehlick 1996: 15). His ideas on human perfectibility were drawn from Darwin’s *The Descent of Man* soon after its publication in 1871:

> we civilised men... do our utmost to check the process of elimination; we build asylums for the imbecile, the maimed, and the sick; we institute poor-laws and our medical men exert their utmost skills to save the life of everyone to the last moment.... Thus the weak members of society propagate their kind. No one who has attended to the breeding of domestic animals will doubt that this must be highly injurious to the race of man (Darwin as quoted in Marks 1999: 33-34).

Prior to it becoming unthinkable after the mass extermination of the disabled and racially different in Nazi Germany, eugenics was a very popular and reputable concept. It was validated by the scientific principles of the day and among its proponents were prominent figures like John D. Rockefeller, Neville Chamberlain, Winston Churchill, Theodore Roosevelt, H. G. Wells, John Maynard Keynes, and H.J. Laski. Moreover, Galton was knighted for his work in 1909 and received many prestigious academic awards for it (Davis 1997a: 19). Despite its fall from favour, eugenic practices still exist today in Western countries in the form of sterilisation, euthanasia
and genetic engineering (Barnes, Mercer and Shakespeare 1999; Drake 1999; Russell 1998; Shakespeare 1998). Eugenics could well be seen as the social exclusion of people with disabilities taken to its logical conclusion.

However, the oppression of disabled people through their definition as "other" usually involves much more subtle process of "social death" (Finklestein 1998: 38) with its fundamental principles interiorised by disabled people in the form of a "psychological eugenics" which keeps the borders between the normal and the abnormal sharply defined. Even outside of institutions this delineation is, as Thomson (1997) describes it, intense.

As a departure from a norm made neutral by an environment created to accommodate it, disability becomes intense, extravagant, and problematic embodiment. It is the unorthodox made flesh . . . The cripple before the stairs, the blind before the printed page, the deaf before the radio, the amputee before the typewriter, and the dwarf before the counter - all testify with their particular bodies to the fact that the myriad structures and practices of material, daily life enforce the cultural expectation of a certain standard, universal subject before whom all others appear inferior (283).

As already indicated, this enforced alterity is built on a hierarchical dualism, disabled/able-bodied, which, like those of man/woman and white/black, exclude the margins by privileging the unexamined centre. Thomson (1997) has developed a new term for the superior pole of this binary, the 'normate' which 'usefully designates the social figure through which people can represent themselves as definitive human beings'. She goes on to say 'this neologism names the failed subject position of cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundary' (8).

In other words, in terms of a disability discourse, the social identities of those who consider themselves to be normal (or non-disabled or able-bodied) are secured only through a process which involves the systematic social exclusion and marginalisation of others ("the disabled"), who are identified in terms of their deviance from an imagined ideal (Swain and Cameron 1999: 75).

The ways in which we tend to exclude the disabled body from what is deemed preferable and powerful reveals much about what we value and will form a central platform of analysis in Chapter Three when disability as an identity is interrogated. But for now it will suffice to say that, although the oppression of disabled people may well have begun with their exclusion from standard forms of social life, it has been driven down deep into their inner cores.
Health as a Key Norm

The concept of "health" is central to the development of our understanding of "disability" as it is one of the basic criteria, alongside the ability to work, for being considered able-bodied. To properly comprehend disability as a concept which has been devised to suit the purposes of particular social and political aims, it is vital to understand the category against which it has been defined. Apart from the fact that a healthy body is usually considered to be an able body, it can be argued that health is fundamental to the achievement of all other norms. George Canguilhem argues that 'Man [sic] does not feel in good health - which is the definition of health - except when feeling not only normal - adapted to one's milieu and its demands - but normative, capable that is of pursuing new norms of life. The ill person is ill by incapacity to tolerate more than a single norm... abnormal not because of the absence of norm, but because of the incapacity to be normative' (as quoted in Gordon 1998: 183). Viewed in this way, health can be said to be a key norm, a necessary factor in the attainment of all other social norms (Osborne 1997).

To explore the concept of health via the techniques of genealogy requires a process that Foucault (1991c) refers to as 'eventalisation'. This involves unseating the belief that historical 'events', in this case the birth of health as a concept, follow an ineluctable pattern of cause and effect. This is achieved by what Foucault refers to as a 'breach of self-evidence' by which it can be demonstrated that 'things weren't as necessary as all that' (83). The often taken-for-granted assumption about health is that it was always a problem whose logical solution involved the surveillance and examination of individual bodies. However, the process of eventalisation can reveal that it wasn't a matter of course that health became perceived and treated the way that it did, that it was, in fact, the result of a 'multiplicity and plural[ity] of causes' which were formed in the 'connection, encounters, supports, blockages, plays of forces, strategies and so on' (84) which comprise the conditions which came together to influence the operation of early liberal government.

While health is classically defined as a state of individual well-being, its main utility from the nineteenth century onwards has been in the maintenance of a newly constructed workforce (Henriques et al. 1984: 132). Liberalism's commitments to economic freedom and the creation of wealth were tied to the development of capitalism, and both liberalism and capitalism were in agreement that the creation of wealth relied on the existence of a healthy pool of labourers. Rabinow (1991) argues that 'the relationship between the economic changes that resulted in the accumulation of capital and the political changes that resulted in the accumulation of power' (17) is complex and cannot be explained in terms which prioritise one over the other. Foucault believes that 'each makes the other possible and necessary; each provide the model for the other' (Foucault as quoted in Rabinow 1991: 17). In either case, the powers which liberal government developed to control the health of its citizenry 'was, without question, an
indispensable element in the development of capitalism; the latter would not have been possible without the controlled insertion of bodies into the machinery of production and the adjustment of the phenomena of population to economic processes' (Foucault 1978: 140-141).

The surveillance of bodies which was necessary to the ends sought by government and industry was achieved through the development of a new concept, that of the population (Pasquino 1991: 115-116). ‘Governments perceived that they were not dealing simply with subjects, or even with a "people," but with a "population," with its specific phenomena and its peculiar variables: birth and death rates, life expectancy, fertility, state of health, frequency of illnesses, patterns of diet and habitation’ (Foucault 1980g: 125). To be able to govern effectively necessitated the development of intricate networks of knowledge surrounding the condition of its people. As Rose (1996b) states, the belief was that: ‘legitimate government will not be arbitrary government, but will be based upon intelligence concerning those whose well-being it is mandated to enhance’ (44). This knowledge is then reframed in relation to the way that government interacts with its subjects, both through its policies and in its influence, via medical intervention, over individual behaviour. As Foucault (1980b) described it, health became an imperative, ‘at once the duty and objective of all’ (170).

The series of interventions and regulatory controls which were necessary to the surveillance and control of this newly formed category of human life was achieved by way of ‘a biopolitics of the population’ (Foucault 1978: 139). Whereas sovereign power had been symbolised by its ability to put to death those who fell out of line, “biopower” functioned by exercising control over life (140). This was achieved in two ways, first by ‘the spread of normalisation [which] operates through the creation of abnormalities which it then must treat and reform’ and, second, by keeping constant watch over the population and devising ways of measuring any deviations from the norm (Rabinow and Dreyfus 1982: 196). It is the latter which will be the focus of the following section, the purpose of which will be to demonstrate how the exercise of power has come to depend on the accumulation of knowledge, knowledge which, although it is purported to simply reveal existing “truths” in relation to its objects of study, actually creates the objects about which it speaks.

**Power, Knowledge and Disability**

... power will be exercised by virtue of the mere fact of things being known and people being seen in a sort of immediate, collective and anonymous gaze (Foucault 1980a: 154).

Systems of government have not achieved their constructions of disability in a purely arbitrary fashion, nor have they had to enforce them by violent means. Rather, in the manner of the liberal administrative state, they have operated through a field of discourse created within the human sciences to name the problem and to devise ways of dealing with it. To understand how
this operates, we need to briefly review Foucault’s arguments about the relationship between power and truth. When Foucault (1977c) argues 'there is no power relation without the correlative constitution of a field of knowledge' (27), he is referring to a relationship which is not easy to grasp because it flies in the face of the humanist belief that power suppresses knowledge and, thus, that “the truth” can only emerge when oppressive power regimes are overthrown (Foucault 1980c: 52). Yet, Foucault makes the case that power and knowledge cannot be separated in this way because, fundamental to the exercise of power is the ability to create "the truth". In the case of absolutist rule, the penalties for challenging prevailing systems of belief are high. Consider the Inquisition which burned dissenters at the stake and declared Galileo a heretic in 1633 for proposing that the earth revolved around the sun. Liberal democracies, however, rely on a much more subtle and complex relationship between power and knowledge which operates in both directions.

The exercise of power itself creates and causes to emerge new objects of knowledge and accumulates new bodies of information…and, conversely, knowledge constantly induces effects of power…It is not possible for power to be exercised without knowledge, it is impossible for knowledge not to engender power…The two are not depicted as having an independent existence. They are coterminous (Townley 1993: 20).

It is through discourse that power and knowledge are joined. ‘In the end, we are judged, condemned, classified, determined in our undertakings, destined to a certain mode of living or dying, as a function of the true discourses which are the areas of the specific effects of power’ (Foucault 1980d: 95). It is possible to govern a people without force by devising ways of thinking which become unquestionable. The belief, for example, that certain people cannot work or are otherwise dysfunctional has been rendered authentic by the definition and diagnoses of medical professionals who are guided by medical discourse. This knowledge has resulted in the development of various points for the insertion of power in the lives of people thus categorised as dis-abled, such as excluding them from mainstream society, subjecting them to constant surveillance, educating them in certain ways, and defining how they should think and act so as to attain the highest degree of normality possible.

A central point here is that, in its modern configuration, power achieves its potency, not through repression, but by generating new ideas, definitions and practices. Foucault (1977c) expresses it thus: ‘We must cease once and for all to describe the effects of power in negative terms: it “excludes”, it "represses”, it "censors”, it "abstracts”, it "masks”, it "conceals". In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him [sic] belong to this production’ (194). In keeping with this view, the disabled individual has been produced through various discourses. By developing a field of knowledge which is based on the observation, measurement, and partitioning of bodies, new ways of controlling people’s movements have been devised and justified. Eventually this control is no longer overtly disciplinary, it functions at the level of
personal interest, and disabled people begin to see themselves as defined through their own choices. ‘If... power is strong this is because, as we are beginning to realise, it produces effects at the level of desire (Foucault 1980c: 59).

The medical discourse which has provided the knowledge base for our current understanding of disability has its origins in the “germ theory” of disease. Prior to the discovery of a biological mechanism of disease, ill health and disability were thought to have been the result of supernatural causes. But with the emergence of a natural object of causation which could be studied and controlled came a whole new understanding of physical impairment. Disability became medicalised and those who were "afflicted" could be diagnosed and treated and, even if their conditions were resistant to intervention, they would remain within the realm of surveillance of the medical "gaze". They would be counted, compared, categorised, examined, experimented upon, named, and passed judgment upon and they would see themselves and be seen in whole new ways.

As has already been discussed, the most potent of the medical techniques which have been used to construct disability as a governable entity has been the process of naming it. What was formerly a disparate collection of physical differences which were largely absorbed by the small rural communities that prevailed in pre-industrial times, emerged as a social category which linked those who were impaired to growing systems of medical care and excluded them from access to the labour market. Initially, in the eighteenth and nineteenth centuries, this process was performed by doctors in their role of distinguishing between the "deserving" and "undeserving" poor which, as Hahn (1986) argues, was based on assumptions which were ‘little more than a “cultural invention”’ (131). This practice of naming disability may have created different definitions to suit the particular purposes of different times, but it has been uniform in its capacity to ensure that physicians ‘have exercised cultural and social authority’ (Donahue and McGuire 1995: 51).

This ability to affect the "conduct of conduct" on an individual and social level has had a massive impact on the people declared disabled over the last three centuries. Some of these have been discussed earlier in this chapter where the institutional separation of able-bodied and disabled bodies was described. Medicine played a vital role here, with disabled people becoming both the subjects and objects of expert knowledges. This was intensified when rehabilitation entered the spaces of confinement in the early twentieth century, securing a place for medicine as ‘the principle agency charged with the restoration of impaired labour power’ (Patterson and Hughes 2000: 38). In casting disability as a "problem" that could be "fixed", or at the very least ameliorated, medical discourse led the transition from the period exemplified by the "freak show" where 'extraordinary bodies' were seen as indelible reminders of what lay beyond the boundaries of normality (Thomson 1997) to a new era where what was constituted as abnormal invited an infinite range of interventions.
Trent (1998) demonstrates this shift in perspective in his analysis of the display of ‘primitives and defectives’ at the St Louis World Trade Fair in 1904. While the bodies which drew crowds to freak shows ‘produced a generalised icon of corporeal and cultural otherness that verified the socio-political status quo and the figure of the unmarked normate, the ideal subject of democracy’ (Thomson 1998: 79-80), the same kinds of physical differences were portrayed in the World Trade Fair of 1904 as social problems which could be shown to respond favourably to the modalities of medicine, education and a flourishing array of social sciences. It is not that the human exhibits at the World Trade Fair were considered any less of a reminder of what the ideal citizen must avoid being or appearing to be. What was added, however, was the premise that science could intervene and resolve the abnormalities which stemmed from disparities based on race, gender, form and function. While doctors had been able to utilise “freaks” as examples of abnormal physiology to shore up the norm, their power became limitless when the norm became defined as attainable by all with the help of medical technology (Trent 1998: 210).

The growing confidence that disability could be brought under control coincided with the emergence of a range of professions which expanded the knowledge base and with it the number of points at which regulatory and exploratory measures could be brought to intervene in the lives of disabled people. During the twentieth century disability began to be administered by government programmes based on the knowledge being produced within the human science disciplines of economics, sociology, psychology, psychiatry and statistics. The transformation of this knowledge into disciplinary procedures marked the development of the less tangible yet more powerful connection between the state and the disabled, and was carried out by a new band of experts such as psychologists, social workers, occupational therapists, rehabilitation counsellors, physiotherapists and special education teachers. This growing infiltration of disciplinary measures into the lives of disabled people meant that there was less need for incarceration, a procedure which, as the demands for more humane treatment increased, became too expensive to maintain. And as disabled people ‘emerge[d] from the closed fortresses in which they once functioned and [began] to circulate in a “free” state’, the ‘methods of control’ over their lives became more flexible and more subtle (Foucault 1977c: 211).

The rise of the “helping professions” as an adjunct to medical discourse has not only suited the liberal democratic mechanism of governing at a distance, but also the associated belief that market forces should prevail. Disabled people have become clients in a range of services, initially embedded in state sponsored welfare programmes, but increasingly run by private enterprise, and, under the gaze of a team of experts, are being encouraged to take more and more responsibility for their own welfare.

There is no need for arms, physical violence, material constraints. Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance
over, and against, himself. A superb formula: power exercised continuously and for what turns out to be a minimal cost (Foucault 1980a 155).

The surveillance which both produces knowledge and ensures its insertion in people's lives is the vital link between power and the "truths" it creates and rests upon. Disability, now a seemingly self-evident physiological fact, has in reality been developed under the gaze of experts and is continually being recreated to serve particular political aims. Yet it is no longer necessary to engage in the dividing practice of institutionalisation to ensure that the partitioning between "the norm" and "the other" remains intact as the knowledge which is produced by the human sciences filters down into what is considered to be common sense such that all people, including and especially disabled people, collude in the process of ideological segregation.

The Ideology of Rehabilitation

To conclude the genealogical analysis of disability it is important to highlight what Anspach (1979) has referred to as 'the ideology of rehabilitation' (771). I suggest that rehabilitation is a concept which epitomises all of the basic elements which have come together in the constitution of disability. It is embedded in the idea that citizens must achieve productivity through the disciplines that stem from employment and the timetable, it works to govern individuals at a distance by immersing them in a field of expertise which serves to guide their aims and actions, and it is representative of the imperative placed on each and every citizen of advanced liberal democracies to strive to emulate the norm. When I use the term "ideology" here I do not intend it to be understood in the traditional sociological sense of a tool wielded by an oppressive regime, but rather as a rationality, a way of thinking which has permeated our Weltanschauung via the diffuse network of power relations fundamental to contemporary liberal societies.

Rehabilitation is based on a principle of reform very similar in many ways to that which has informed the operation of the penitentiary system as explored by Foucault (1977c) in Discipline and Punish. In both these contexts, rehabilitation's significance relies, not on its ability to actually eliminate the problems it is supposedly designed to address, but to reinforce a system of disciplinary power based on such classifications.

One would be forced to suppose that the prison, and no doubt punishment in general, is not intended to eliminate offences, but rather to distinguish them, to distribute them, to use them: that it is not so much that they render docile those who are liable to transgress the law but that they tend to assimilate the transgression of the laws in a general tactic of subjection (Foucault 1977c: 44).

In keeping with the above, Rabinow & Dreyfus (1982) argue that 'penitentiaries, and perhaps all normalising power succeed when they are only partially successful' (196). This is just as pertinent to the physical, behavioural and psychological rehabilitation that is imposed upon
disabled people as it is to the "moral rehabilitation" designed to reform criminals. The ideology of rehabilitation can only continue to be justified as a principle for reinforcing certain standards if those standards consistently fail to be met.

In this way it can be argued that the "delinquent" and the "disabled person" serve a similar purpose in society. Both classifications are based on the idea of deviation from acceptable standards and are seen to justify disciplinary measures which range from surveillance and incarceration to self-government through the guidance of experts. Foucault (1977c) argues that '[t]he prison cannot fail to produce delinquents' (266). This is because the punitive system relies on the naming of a group formerly not conceived and then proceeds to marginalise its constitutive population in such a way as to leave them with no alternative other than to behave in the ways prescribed by their classification. Foucault (1991e) argues further that:

For the observation that prison fails to eliminate crime, one should perhaps substitute the hypothesis that prison has succeeded extremely well in producing delinquency... So successful has the prison been that, after a century and a half of "failures," the prison still exists, producing the same results, and there is the greatest reluctance to dispense with it... (231, 232).

The same can be said for the relationship that has developed between rehabilitation and disability in that rehabilitation has been extremely successful in producing and reproducing "disability" in its contemporary form. True to its grounding in medical discourse, rehabilitation focuses on disability as an individual problem which requires individual change. As with delinquency, which is seen to be an individual aberration rather than a phenomenon which has its roots in social inequality, the social origins of disability are largely ignored. Consider the following very recent description of the aims of rehabilitation:

Rehabilitation is a goal-oriented and time-limited process aimed at enabling an impaired person to reach the optimum mental, physical and/or social functional level, thus providing the individual with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example, by technical aids) and other measures intended to facilitate social adjustment or re-adjustment (Healey 2000: 2).

Under this definition, disability is located within the individual and remedial action is diverted to the person concerned as a matter of individual responsibility. There is no consideration that disability is created by a social environment which excludes people who do not fit the norm and, as such, rehabilitation is assured of maintaining its power to define and marginalise.

When viewed from Foucault’s (1977b) perspective that the world as we understand it today has been built, not from a firm and sequential continuity, but from a fragile and discontinuous
lineage of ‘accident and succession’ (142), rehabilitation can be understood as the result of a collision of elements which, if the conditions for their fusion had not been as they were, may have dispersed or merged in a different way. Yet, due to a series of not always connected, yet mutually reinforcing, events, such as the advent of modern warfare, the development of workers’ compensation legislation, the expansion of medical discourse, the birth of the welfare state, and the emergence of a range of health and welfare professionals whose purpose was to facilitate the lives of the disadvantaged, rehabilitation evolved as a potent governmental tool.

Although work-related accidents had already started to attract attention by the end of the nineteenth century, it was not until the First World War that rehabilitation became a primary governmental aim. Thousands of men who would once have died on the battlefield were saved to become amputees and otherwise disabled veterans and, with the boom created by the wartime upsurge in manufacturing, there was a greater need than ever to restore as many people as possible to their place within the system of disciplines that comprises the labour force.

The response to the disabilities incurred during the first world war was largely mechanical. Technology could be utilised to restore the function of those wounded by battle. Prior to this the only aids available to the “cripple” were the wooden leg and the crutch, but after the horrendous casualties wrought by the war in Europe, the replacement of body parts became big business.

But prosthesis is not only the pieces of wood, iron, now plastic that replace the missing hand or foot. It is also the very idea that you can replace. The image of the maimed person and of the society around him becomes prosthetic. Replacement, re-establishment of the prior situation, substitution, compensation - all this now becomes possible language (Stiker 1999: 123-124).

Indeed, prosthetics formed part of what was to become a larger rationale. Rehabilitation was to develop into a complex field of expertise covering a wide range of discourses whose purpose was not only to restore the patient’s former appearance and function, but also to emphasise ways of thinking and behaving which were consistent with “normality”.

The emergence of the social survey in the late 1940s helped to bring chronic illness and disability even more fully under the gaze of medicine and its associated discourses (Armstrong 1983, 1995). With this influx of statistical input, the knowledge base of these new fields was able to expand very rapidly and it was at this time that the professions associated with rehabilitation gained a foothold within the institutions of higher learning. A course for social work was set up at the London School of Economics in 1954 (Drake 1999: 53), a World Federation of Occupational Therapists was formed in 1952, and in 1954 the first international congress of occupational therapists was held at Edinburgh (Pound et al. 1997). Since then, occupational therapy has occupied a key place in the assembly of rehabilitation professions given its focus on returning the disabled or chronically ill person to a state of normality in relation to both work
and living skills, and its 'knowledge of anatomy, physiology, medicine, surgery, psychiatry, and psychology' (ibid. 335).

This growth of professional intervention into the lives of disabled people was accompanied by an explosion of the literature on rehabilitation. Barker et al. (1953) refer to 'an annotated bibliography of 5000 items issued during the years 1940-1946' and remark that 'the publication has certainly not been less in later years' (366). Anspach (1979) suggests that these texts are 'infused with optimism and a belief in human perfectibility, imbued with a belief in the efficacy of individual effort' and, in consequence, 'rehabilitation agents promulgated a rhetoric of "coping" with disability and "adjustment" to the prevailing normative structure' (771). While the words "coping" and "adjustment" may seem an innocent enough description of the processes through which a disabled person must pass to overcome his or her disadvantage, they are loaded with assumptions based on the belief that disability is a personal deficit to be overcome from within.

The ways in which these assumptions enter texts - even those supposed to take issue with the medical model - can be illustrated by the work of Anselm Strauss (1984 [1975]), a sociologist of some standing. Strauss’s text on the experience of chronic illness and disability intended to educate the full gamut of health professionals who were increasingly engaging in the rehabilitation business. In his discussion of ‘normalisation’, for example, he observes that those who successfully adjust:

... simply come to accept, on a long-term basis, whatever restrictions are placed on their lives. Like Franklin Roosevelt, with his polio-caused disability, they live perfectly normal (even supernormal!) lives in all respects except for whatever handicaps may derive from their symptoms or their medical regimens. To keep interaction normal, they need only develop the requisite skills to make others ignore the differences between each other in just that unimportant regard (87).

Strauss's work is to be applauded, along with the work of other symbolic interactionists such as Goffman (1963) and Charmaz (1983, 1987), for its challenge to medicine’s preoccupation with the functional aspects of disability at the expense of the ways in which people actually experience it. However, while such authors focus on the personal ramifications of disability, they neglect to analyse its social construction and, as Armstrong (1983) argues, ‘the effect of their stance is to have strengthened the power of the gaze of the new medicine to the essentially subjective’ (115).

Over the past three or four decades the concepts of “rehabilitation” and “normalisation” have become virtually synonymous. The term “normalisation” was first used in Scandinavia in the 1950s by Karl Grunewald and Bengt Nirje in Sweden and Nils Bank-Mikkelsen in Denmark (Cocks and Stehlik 1996: 19-20). It began as a concept used to describe the assimilation of intellectually disabled people into the community as a function of deinstitutionalisation, but it
was picked up by Wolfensberger in the late 1960s and has continued to influence the development of general rehabilitation policy in English speaking countries since that time (Wolfensberger 1969, 1972, 1992). In essence, "normalisation" is an open acknowledgment of rehabilitation's aim to reinforce certain standards of behaviour, function and appearance among those to be assisted and reformed.

Another feature of normalisation is that it invariably falls short of its stated goals with the result that disabled people continue to present a cogent reminder of the other side of normality. Two recent studies illustrate this. The first, by Ochs and Roessler (2001), concludes that people with disabilities have not been as successful as their non-disabled cohorts in finding employment because they lack the characteristics of 'career maturity' and 'personal flexibility' (170). The students in this study were measured for these competencies using a range of scales which attach numerical values to the qualities being assessed. From these measures it was concluded that disabled students need to be taught new skills which will enhance their inferior levels of 'career decision-making self-efficacy beliefs', 'career outcome expectations', 'intentions to engage in career exploratory beliefs' and 'vocational identity' (175). Nowhere is it mentioned that disabled people may in fact be faced with lower employment rates due to job discrimination and/or social and environmental constraints. The assumption is, as always, that the problem, and therefore the solution, lies within the individual.

The second study by Livneh (2001) explores the ways in which disabled people adapt to their conditions and circumstances according to another quantitative measure, a very popular one these days, the QOL (pronounced quoll). QOL is an acronym for "quality of life" and is based on a variety of scales which ascertain 'one's ability to effectively re-establish and manage both the external environment and one's inner experiences (cognitions, feelings, behaviors)' (156). Someone with a high QOL is performing well in a normative sense and is seen to be adapting comfortably to disability or chronic illness. On the other hand, someone with a low QOL is exhibiting thoughts and behaviours which are problematic for their rehabilitation. Once again, the emphasis here is on personal adjustment which completely neglects the political context in which disability is played out. The calibration of individuals according to these precepts serves the purpose of reinforcing the norm, not of actually offering disabled people a better "quality of life".

Studies such as these demonstrate that the quantification of human attributes and experience has come a long way since its instigation in demographic statistics in the eighteenth century. Now calculations are made, not just about the more abstract category of the population, but also in relation to individuals, marking their inadequacies, mapping their desires and delineating their needs. When numerical values are attached to concepts such as 'career maturity', 'personal flexibility', 'vocational identity', 'coping', 'adjustment', and, more broadly speaking, 'quality of life', they tend to become indelible measures of disabled people's identities, abilities and possibilities.
And, as with the IQ test, it is difficult or even impossible to escape their definition once one is marked by these scores.

Thus it comes about, through the development of modern forms of governance and the fields of knowledge and expertise that fuel them, that those who are viewed as physically incapacitated are assigned an identity and a social location which marks them as Other. To recognise, via genealogy, that this identity is a social construction is to present a serious challenge to the biomedical/psychological view which assumes that the inner distress and self-esteem problems which accompany disability are natural reactions to personal tragedy which must be remedied by way of expert guidance. A genealogical view of the disabled identity demonstrates, conversely, that these scientifically based "responses" to illnesses and impairments are, in actuality, the basis for the creation of the category of disability and the imposition of a marginalised status on those medically defined as "disabled". The disabled identity, therefore, does not stem from an aberration of the individual psyche, it emerges from the calibrations, inscriptions and disciplinary logics which have been devised to influence the shaping of a preferred way of living and being and, as such, is not immutable.
CHAPTER THREE

The Making of the Disabled Identity

Disability is a form of social oppression involving ... the socially engendered undermining of [disabled people's] psycho-emotional well-being (Thomas 1999b: 60).

The genealogical analysis framing Chapter Two provides a historical perspective of disability which reveals its construction as a counterpoint to the norm. What should be apparent from this analysis is how the structural oppression of people with impairments has come about in modern times through the exclusionary practices and discriminatory views which are grounded in this conceptual division. What remains to be explored are the effects that this kind of marginalisation has on the inner lives of disabled people. At the heart of my thesis is the belief that people who acquire disabilities, whether it be through sudden injury or accident or the gradual encroachment of chronic illness, are faced with identity crises or 'biographical disruptions' (Bury 1982) which are directly linked to the social construction of disability as an inferior status. In other words, due to its socio-political evolution as an unacceptable physical difference which is believed to exist in direct opposition to much of what is most valued in contemporary society, impairment results not only in physical suffering such as pain and incapacity, it brings with it a 'spoiled identity' (Goffman 1963) which multiplies this suffering many times over.

Prior to becoming disabled, certain privileges and statuses are taken for granted. Much in the same way that "whiteness" is an invisible insignia of the norm, "ablebodiedness" is also an unquestioned, unremarked upon state which only becomes notable in its absence, the difference being, of course, that one can become disabled, while race, gender and ethnicity are imposed at birth. To become disabled is to be relegated to a marginalised status in society and brings into high relief for the disabled person the advantages accorded those who inhabit the unacknowledged "centre". To become disabled is to lose access to these privileges and, in so doing, to begin to be defined in very different ways. These processes are subtle. One is not initiated into the ranks of the disabled by being subjected to the undisguised hatred that met those marked by the Star of David in Hitler's Germany (Russell 1998: 18-19). Rather, the recruitment of disabled subjects into inferior subject positions derives from the creation of identities which seem natural and very much the responsibility of the individual psyche. Although the loss of one's comparatively privileged subject position may be very sudden and momentous according to the particular nature of the accident, illness or injury, the overall summoning to a new level of identification is a gradual process whereby the doubts from within, the stares and snubs from without, and the lack of access to previously available social locations and resources erode one's prior claim to social acceptability.
Typically, with the onset of disability, the impaired feel an acute sense of displacement, living as they do in a culture that privileges strength, beauty, and health over frailty, deformity, and illness. They correctly perceive that cripples generate discomfort, that wounds disturb, that damaged bodies affront (Rinaldi 1996: 821). Nevertheless, non-disabled people rarely admit that they harbour negative feelings towards those who are disabled. 'Public, verbalised attitudes toward disabled persons are on the average mildly favourable'. However, '[i]ndirect evidence suggests that deeper unverbalised attitudes are more frequently hostile' (Barker et al. 1953: 84). Young (1990) corroborates the existence of such subconscious discrimination and explains that it results in 'avoidance, aversion, expressions of nervousness, condescension, and stereotyping' (133). Because this behaviour is often subtle, it leaves the recipient feeling disturbed but with no means of redress, and even if a challenge is made it 'is met with denial and powerful gestures of silencing, which can make oppressed people feel slightly crazy' (134).

Alongside and often resulting from this kind of negative treatment is the development of internalised oppression, that is, the 'feelings of inadequacy, self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment' (Barnes, Mercer and Shakespeare 1999: 178). According to the medical model, these feelings are part of an individual psychological reaction to loss and personal tragedy and can only be remedied through the disabled person learning to cope. However, when viewed from a social constructionist perspective, internalised oppression can be seen to result from the imposition of a marginalised identity.

Internalised oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusion, the negative self images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives (Mason as quoted in Marks 1999: 25).

The recognition that the identity loss which accompanies disability is not a personal crisis, but rather the result of social forces which benefit from the construction of disability as an inferior status, is the first step in devising an appropriate remedy. For the solution to this loss lies not in learning to "cope" with it, but through challenging it at its roots by recognising that the possession of an inferior identity is both contingent and expedient and need not be that way at all.

'The purpose of history, guided by genealogy, is not to discover the roots of our identity but to commit itself to its dissipation. It does not seek to define a unique threshold of emergence, the homeland to which meta-physicians promise us return; it seeks to make visible all those discontinuities that cross us' (Foucault 1977b: 161). Herein lies the real power of genealogy. By
acknowledging that we do not contain an essential core of identity which has been masked by oppression but rather that we have been defined through structures of normalisation, it becomes evident that our liberation from these structures does not lie in overturning this power but in harnessing it for our own self-definition. I quote liberally from Connolly (1998) because he expresses this point so well:

If you think that a stubborn source of evil resides in the paradoxical relation of identity to the differences through which it is constituted, you might deploy genealogy to expose the constructed, contingent and relational character of established identities. Doing so to contest the conversion of difference into otherness by individuals and collectivities striving to erase evidence of dependency on the differences they contest. Doing so to open up other relational possibilities between interdependence, to contending identities by subtracting the sense of necessity from every identity (110).

It is the 'subtracting [of] the sense of necessity from every identity' that is vital to my objectives. It is my contention that, if we can discover through the inspirations of Foucault's genealogical method that the ways we see ourselves and are perceived by the world are but a convenient construction devised to aid in mechanisms of "government", then we can choose to think and feel in different ways.

Identity in Crisis

It is commonly agreed by social theorists that identity as a concept is in crisis (Anderson 1997: 5; Rose 1996a: 169). It is a term which we all use very loosely to describe certain aspects of ourselves and our location within society. Indeed, its ubiquity is such that Weigert et al. (1986) refer to it as a 'cultural cliché' whose meaning has become so vague and all-encompassing as to render it almost useless as a sociological concept (21). But its state of crisis goes much deeper than this and is due to the fact that its modernist associations with unity, continuity, and autonomy have been severely challenged within the practices of deconstruction. Thus, as Hall (1996) admits, identity is a concept which is operating 'under erasure', that it is 'no longer serviceable - good to think with - in [its] originary and unreconstructed form' (1). However, as he goes on to argue, 'what this decentring requires - as the evolution of Foucault's work clearly shows - is not an abandonment or abolition of "the subject" but a reconceptualisation - thinking it in its new, displaced or decentred position within the paradigm' (2).

I concur with Hall and argue that, although the declaration that the subject is dead contributes to the recognition that our identities are created through discourse, it is vital to acknowledge how the view of the self as an essential, unified, interiorised being still affects the way we think. Deleuze (1988) touches on this process of transition when he reminds us that '[w]e continue to produce ourselves as a subject on the basis of old modes which do not correspond to our problems' (107). We live in a state of tension between the experience of ourselves 'as a series
of flows, energies, movements, and capacities, a series of fragments or segments capable of being linked together in ways other than those that coagulate it into an identity' (Grosz 1994: 197-8) and the deep connection we have to a unified, continuous, stable conception of self. I contend that the resolution of this tension does not lie in forfeiting one for the other, it requires understanding each of them in their historical contexts.

Descartes' famous statement, 'cogito ergo sum' - 'I think, therefore I am', is the fundamental premise for the liberal argument 'for a unified self, a knowing subject, that is transparent to itself, and for clear rational thought as the source of control, and autonomy' (Griffiths 1995: 79). This concept of unity, of the sameness and continuity of an individual through time, is featured in the lexical origins of the word "identity" from the Latin idem which means "same". Locke (1969) followed on from this idea of a continuity of consciousness and argued that 'as far as this consciousness can be extended backwards to any past action or thought, so far reaches the identity of that person' (212). An essential feature of the construction of identity by the early liberal philosophers, then, was the belief that we are cohesive, accountable beings.

In addition to the belief that identity is based on "sameness" and continuity, the traditional humanist understanding of identity also places it in terms of its distinctness, a view which is based on the belief that we exist in isolation from any social influence, that we possess an essential identity that is prior to and distinct from the outside world. As Dunne (1995) argues the "self" is believed to be 'immediately, transparently and irrefutably present to itself as a pure extensionless consciousness, already established in being, without a body and with no acknowledged complicity in language, culture, or community' (Dunne 1995: 138). The origins of this concept of distinctness can be traced through the etymology of the word "self" which comes from the Latin ipse which, according to the Oxford English Dictionary, is meant 'to indicate emphatically that the reference is to the person or thing mentioned and not, or not merely, to some other'.

Elias (2000) argues that the idea of the self as a unified and distinct entity, separated from all around it, originated in Rousseau's Confessions. Rousseau's self-narrative explorations reveal an individualised and autonomous self that had previously remained 'below the threshold of description' (287). And from this came the increasingly differentiated concept of the human being that still wields so much influence today.

The conception of the individual as homo clausus, a little world in himself who ultimately exists quite independently of the great world outside, determines the image of man in general. Every other human being is likewise seen as homo clausus; his core, his being, his true self appears likewise as something divided within him by an invisible wall from everything outside, including every other human being (ibid.).
This wall between one's "true identity" and the social and material world underscores the view that positivist science takes towards the study of human beings. The philosophical and scientific construction of this wall 'did not appear to those thinking about it at this stage as an act of distancing but as a distance actually present, as an eternal condition of spatial separation between a mental apparatus apparently locked “inside” man and “understanding” or “reason”, and the objects “outside” and divided from it by an invisible wall' (Elias 200: 292).

The understanding of identity in relation to its philosophical origins can shed a great deal of light on how the "disabled identity" is experienced. The notion that identity is unified is a very convincing one as it is reinforced constantly by the way our experiences appear to connect in a logical progression. Our identities can be felt to exist as narratives, stories which link together who-we-are-now with who-we-were and who-we-will-become. Although in actuality these narratives have to be very flexible to accommodate the diverse range of new inputs which enter a person's realm of experience, they appear to be very stable and unitary. The person who becomes disabled experiences a massive rupture to the stability and flow of this narrative and this results in the 'biographical disruption' that Bury (1982) describes in relation to the onset and negotiation of disability and chronic illness. If it were not for the assumption that our identities have a stable and continuous form, bodily disruptions would more easily join the multitude of other variations which constantly redefine our lives.

How then can the decentred, fragmentary identity which is integral to the postmodern self become reconciled with its modernist counterpart? Sarup (1996) engages with this issue by suggesting that '[i]dentities are stitched together out of discontinuous forms and practices. The representation of identity is an ongoing process, undertaken on many levels, in different practices and sites of experience. Identity is articulated in multiple modalities - the moment of experience, the mode of writing or representation . . . and the theoretical modality' (Sarup 1996: 40). Within this description there is a recognition that these multiple identities are 'stitched together', even though the fabric from which they are joined may be woven from threads of vastly different textures. Ewing also points to this coexistence of representational forms when she argues that 'as long as an individual is able to maintain contextually appropriate self-representations in interaction with others, he or she may experience a sense of continuity despite the existence of multiple, unintegrated or partially integrated self-representations' (as quoted in Sands 1996: 177).

In keeping with the recognition that identity exists as both a fabrication and a perceived "truth" that we find difficult to shake, Sands (1996) "recommend[s] that we assume the postmodern stance of "positionality," that is, assume that the self/identity both exists and does not exist (as an "essence"), depending on the context in which we are using the concept. In making this assumption, we recognise that self/identity can be "multiple, contradictory, and in process" (177). This brings to mind the quantum theory of mechanics which attempts to solve the
dilemma of matter which sometimes appears to behave as a wave and at other times a particle. Identity is metaphorically similar. It is simultaneously a diverse set of fluid identities and a stability which people build into a narrative which makes them feel whole.

Rose (1996a) expands the discussion of the dual nature of identity by pointing to 'the peculiar fact that at the very moment when this image of the human being is pronounced passé by social theorists, regulatory practices seek to govern individuals in a way more tied to their "selfhood" than ever before, and the ideas of identity and its cognates have acquired an increased salience in so many of the practices in which human beings engage' (169). This intensification of the focus on the individualised self is more than a harking back to traditional modes of thinking about the subject, it is representative of a system of power relations which is disguised by the very notions that it disrupts.

What makes us such an effective 'vehicle' for power is the very fact that we seek to see ourselves as free of it and naturally occurring. For Foucault, Rousseau's free and autonomous individual is not merely an alternative, outmoded theory of subjectivity, a quaint forerunner to contemporary discussions. This very model is the one that allows power to conceal itself, and to operate so effectively (Mansfield 2000: 55).

This is why it is so difficult to shift the modernist conception of the self. Our ongoing belief that we are unified beings who are free to choose from the multitude of available lifestyles on offer in contemporary neoliberal society is the key to our ultimate subjection.

Foucault (1982) illuminates the power relations involved in the formation of subjectivity when he supports that '[t]here are two meanings of the word subject... subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power which subjugates and makes subject to' (212). Foucault refers to this twofold signification as assujetissement, a French word which has no English equivalent and has been translated variously as 'subjectivation' (Butler 1997: 11), 'subjectification' (Minson 1985: 44), and 'subjectivisation' (Connolly 1998: 155). I choose "subjectification" as it is a word already in existence which means 'the action of making or being made subjective' (OED) which seems to suit very well Foucault's statement: 'I will call assujetissement the procedure by which one obtains the constitution of a subject, or more precisely, of a subjectivity which is of course only one of the given possibilities of organisation of our self-consciousness' (Foucault 1988i: 253).

Regardless of which word we choose to exchange for assujetissement, its importance lies in its expression of the dual nature of the subject and the insistence this places on its social construction. In defining the subject as such, Foucault at once unseats the assumptions which have supported the belief that the liberal democratic citizen is a free, self-initiating atom, and at the same time demonstrates how these beliefs are tied in with the systems of power responsible
for this lack of agency. In keeping with Foucault's definition of the subject, I propose a set of working definitions for the concepts "identity" and "subjectivity" which place them at either end of Foucault's continuum of subjection. They are very difficult terms to separate and are often used interchangeably. However, while, as in any continuum, there is a great deal of overlap, in their purest, largely theoretical form, they speak of different states, like the particle and the wave. Subjectivity is a term which refers to our inner world, our thoughts and feelings, while identity is representative of the external influences, the labels which are imposed from without.

Woodward (1997), in exploring the constitution of identity through difference, approaches the distinction between identity and subjectivity in a way that is conducive to the particular understanding of the process of subjectification that I wish to pursue here.

Subjectivity includes our sense of self. It involves the conscious and unconscious thoughts and emotions which constitute our sense of 'who we are' and the feelings which are brought to different positions within culture. Subjectivity involves our most personal feelings and thoughts. Yet we experience our subjectivity in a social context where language and culture give meaning to experience of ourselves and where we adopt an identity. Discourses, whatever sets of meaning they construct, can only be effective if they recruit subjects...The divisions which we take up and identify with constitute our identities (39).

This touches on the distinction I am trying to draw between identity and subjectivity, but it falls short of locating them in their political context. Carspecken and Apple (1992) come closer to this kind of analysis when they state that '[i]dentities are constantly claimed, alongside norms and values, in human interactions. In fact, they are internally bound to them. Participants use norms and values to claim identities' (526). For it is the system of norms which define the identities accessible to a particular individual.

It is my contention that identity is the key mechanism for inserting social meaning into personal experience and, as such, can be defined as the main conduit linking power to subjectivity. How we see ourselves and how we feel we are judged by others is a very powerful point of influence and confluence. And it is all the more powerful because we tend to own it completely in terms of "personal" qualities such as self-esteem and empowerment, viewing it as a matter of personal growth and choice, rather than as an artefact of power, a creation of expert knowledges, a potential trap from which it is difficult to escape. Identity is a tool of government, a very powerful organising concept which is pivotal to the technologies of the self which govern our beliefs and behaviours by way of our apparent "choices" and "freedoms".

'Of all the ways of becoming "other" in our society, disability is the only one that can happen to anyone, in an instant, transforming that person's life and identity forever' (King 1993: 75). It is therefore a unique site of subjectification, one which can exemplify with great clarity and
intensity the ways in which identity as a process of labelling, differentiation and social positioning joins the personal to the political, the subjective to that which subjugates. Sullivan (1996), for example, suggests that the person who suffers from a spinal cord injury ‘becomes part of the medical discourse on paraplegia which maintains the person as a particular subject, knowing and experiencing its body in a highly medicalised way, and having the possibilities as a subject constrained by the disciplinary techniques this knowledge imposes’ (as quoted in Sullivan and Munford 1998: 187). Minson (1985) goes to the heart of the issue here with his suggestion that ‘[s]ubjectivities are constituted by, and rendered instrumental to, a particular form of power through the medium of the knowledges or technical savoir fair ‘immanent’ to that form of power’ (45). I wish to extend this by investigating the role of language in mediating the interaction between knowledge and power. Indeed, because language is built on the process of “othering” it constitutes a naming process which defines identity through difference.

A useful starting point in this respect is Hughes’ (2000) description of the construction of disability as a process of ‘invalidation’, an ‘othering process that has both produced and “spoilt” disability as an identity’ (558). He goes on to argue:

*Validity is at the heart of the process of othering. It is the question posed by it and cultural meanings about what constitutes ‘the natural’ - conceived as the inescapably true - is the ground upon which validity is assessed. To be or become invalid is to be defined as flawed or in deficit in terms of the unforgiving tribunal nature and necessity, normality and abnormality over which medical science presides (ibid.).*

Recognising how the “valid” and the “invalid” are created reveals how closely woven are our discourses and the words we use to frame them. Much can be gained from exploring the etymology of such words.

*Both meanings of invalid, the noun which defines a sick or weak person and the adjective which means ‘not valid’ - where valid means sound or true - are based on the same Latin word invalidus which means not strong. When applied to the chronically ill [or disabled person], this sense of physical weakness is often extended by the able-bodied to mean weak in character and the connotation of the adjective invalid as worthless is superimposed on the [disabled] person (Galvin 2000: 47).*

Our words are very powerful tools of representation which are accorded even more potency when they are taken for granted as transparent symbols of "reality". I believe that the "loosening of the ties to our identities", which is the objective of the genealogical approach, can only be fully realised through the development of a clear understanding of the fundamental role that language plays in naming what is "normal" and what is "other".

There are many social theorists who argue for the connection between language and identity (Danziger 1997; Haber 1994; Hall 1997) and a growing number who are beginning to include
this link in their analysis of the disabled identity (Corker 1998, 1999, 2000; Hedlund 2000; Linton 1998; Marks 1999). Indeed, the view that identity is created through language has a long history, beginning with Baldwin (1897), Cooley (1902) and Mead (1934), founders of the sociological field of symbolic interaction, who based their theories on the premise that 'the self is primarily a social construction crafted through linguistic exchanges (i.e., symbolic interactions) with others' (Harter 1999: 677). In the remainder of this chapter I will attempt to contribute to the sociological study of language in relation to disability in the following ways. First, I map the theoretical analyses of the construction of language through difference, from Saussure through Lacan to Derrida. Following this I argue that the semiotic dichotomy of identity/difference is basic to our modes of subjectification and, accordingly, that identity is formed through symbolic systems which rely on the creation of an antithetical Other. I then place this analysis in a Foucaultian framework which recognises the significance of discourse, power and normalisation in the creation of subjects through language. Finally, I attempt to demonstrate how those identified as Other are denied a voice within the system of language which defines them and I develop a critique around current forms of linguistic challenge to explore the possibilities for healing the disabled identity through the subversion of language.

What's in a Name?

Isn't the first question, the one that misfortune itself causes us to forget, this one: why is disability called "dis-ability"? Why are those who are born or become different referred to by all these various names? Why so many categories? Why such dramatics in the face of what happens . . . which can happen to any of us? . . . To name, designate, point out, is to make exist. Our natural assumption is to believe that language expresses the real . . . But, quite to the contrary, language operates, transforms, creates. In one sense, there is no other reality than language. The institution of language is the primary social institution in which all the others are inscribed and, indeed, where they originate (Stiker 1999: 5, 153).

The institution of an identity, which can be a title of nobility or of stigma... is the imposition of a name, i.e. a social essence. To institute, to assign an essence, a competence, is to impose a right to be that is an obligation of being so (or to be so) (Bourdieu 1991: 120).

...by calling them so, people make them so (Rogers et al. 2001: 259)

The idea that the subject is created in the process of naming is central to the work of Althusser (1971) who coined the term 'interpellation' to describe how the practice of subjectification is facilitated by locating the subject in language (146). "Ideology... "recruits" subjects among the individuals... or "transforms" the individuals... by the very mechanism I have called interpellations or "hailing" (ibid.). He goes on to explain:
Interpellation... can be imagined along the lines of the most common place everyday police (or other hailing: 'Hey, you there!...'). The hailed individual will turn around. By this mere one-hundred-and-eighty-degree physical conversion, he becomes a subject. Why? Because he has recognised that the hail was "really" addressed to him, and that "it was really him who was hailed" (and not someone else) (163).

The response of recognition implicit in the concept of interpellation demonstrates the power of the name, the label. It connects our sense of self with society's definition. Thus, our occupation of a subject-position, such as that of a patriotic [or disabled] citizen, is not a matter simply of conscious personal choice but of our having been recruited into that position through recognition of it within a system of representation, and of making an investment in it' (Woodward 1997: 43). The concept of interpellation is helpful, not only because it paves the way for an understanding of the creation of the subject through language, but because it points to the internalisation of oppressive language which is fundamental to the creation of the disabled identity. The language we use and the labels we identify with become so taken for granted that we eventually feel that we actually, inherently are what we have been named. Therefore, to create the possibility for challenging this deeply embedded subjugation, it is necessary to historicise the process of identification through language and, in so doing, to unseat its hegemonic hold.

Ferdinand de Saussure (1857-1913) founded his linguistic theories on three main premises, each of which are relevant to the development of a better understanding of the creation of the disabled subject through language. He argued that language is socially constructed, that the symbols we use to create meaning are arbitrary, and, most importantly for our purposes, that we can only understand the meaning of these symbols through contrasting them with what they are not. When Saussure argues that 'language is not a function of the speaking subject' (quoted in Derrida 2000: 91), he is stating the basic semiotic principle that language is predetermined in its possibilities by the structure, already in place, by which a particular culture governs its realm of linguistic signification. He refers to this structure as la langue which Hall (1997) describes as 'the underlying rule-governed structure of language...the language system' (34). Alternately, there exists la parole which is the individual speech act which expresses itself through this system. Hedley (1999) refers to langue and parole as 'the two different modes in which language exists for us simultaneously: as a system of already encoded meanings and as ongoing open-ended meaning-making activity' (102).

This concept of the system of language and the speaking subject is analogous to Foucault's (1972) explication of the two forms of subjectification, i.e., subjection and subjectivity. Being 'subject to someone else by control and dependence' can be said to rely on the existence of la langue, a socially governed system of linguistic possibilities, while being 'tied to [one's] own identity by a conscience or self-knowledge' is similarly related to the individual speech act, la parole (212). In his earlier work, Foucault (1970) argued that these two realms of language and,
thereby, subjecthood, are connected by simple discourse which transmits politically accepted definitions. When he states that "between these two regions [language and parole], so distant from one another, lies a domain which, even though its role is mainly an intermediary one, is nonetheless fundamental" (xx) I believe that he refers to the space where subjectification takes place, between the set of discourses which overarch our political rationalities and the location of our inner thoughts, guided by our apparent "freedom of choice".

A semiotic perspective is also useful to the analysis of subjectification through language because it demonstrates that meaning is not transparent, that is, that the language we use to describe things does not mirror reality. Saussure (1959) expresses it thus: 'a linguistic sign unites not a thing and a name, but a concept and a sound-image' (166). According to this argument, words are arbitrary, they have no inherent connection to the thing they describe. It is the meaning behind the words, the concepts they bring to mind when they are spoken, that gives them their power. This is why "politically correct" language may be unable to dislodge oppressive identifications, for, if the concepts behind the words remain unchanged, then the new words end up being just as negative in their connotations. Saussure points to this phenomenon when he draws an analogy between language and a chess game, a unit of language and a chess piece:

Suppose that during a game this piece gets lost or destroyed. Can it be replaced? Of course it can. Not only by some other knight, but even by an object of quite a different shape, which can be counted as a knight, provided it is assigned the same value as the missing piece (Saussure 1983: 153-4).

Thus, if new, "politically correct" language begins to take on the meaning of the word it replaces, then the game remains unchanged. For language to liberate, new meanings must emerge, be represented. To stay with the chess analogy, it must be capable of making new "moves".

Saussure uses the terms "sign", "signifier" and "signified" to denote the relationship between the "referent" (the thing itself), the word used to describe it and the concept this word is intended to relay. A sign is the combination of a word (the signifier) with a concept (the signified). Therefore signs contain meanings which go well beyond the material reality of the referent. Bradac (2000) follows on from this by describing the political connotations this kind of meaning formation makes feasible.

A sign links expression to thought, so an interesting possibility is that by influencing expression, one can influence, or ultimately control, thought. Also, by encouraging particular signifier-signified associations and discouraging others, groups can gain or maintain power by channeling thoughts in a power-enhancing direction. If the slogan "war is good" is used often enough, a sign may come to exist that is constituted by the signifier "war" and the signified [good] (500).
I believe that it is this kind of relationship between the signifier, "disability" (and all the other words and phrases which are used to describe impairment), and the very negative concept which is signified, which creates an undesirable identity for disabled people. When someone is named "disabled", they are not being accorded a tag which simply describes a physical or material condition, they are being ascribed a set of oppressive associations which stem from the hypostatisation of an abstract concept.

Finally, and most importantly, Saussure (1959) suspected that 'in language there are only differences' (117). This fits together closely with the stipulation that the symbols we use as signifiers are arbitrary, that they have no inherent relationship with the thing being described. Because of this, a word can only begin to have meaning when it is contrasted with what it is not. From this comes the practice, vital to the mechanics of normalisation, of defining what is "normal" against that which is "other" through the construction of binary oppositions. It is because the politically desirable identity can only be defined in relation to its antithesis, and because this formulation negates any differences that may conceivably exist between these two extremes, that the subjectification of those who fall outside the prescriptions of the norm becomes such a win or lose affair. Thus, when Saussure (1983) argues that '[t]he mechanism of a language turns entirely on identities and differences' (151) he is accurately observing a system of identification which has no room for the recognition of all the greys which exist between "white" and "black".

Lacan drew from Saussure to develop a psychoanalytical theory of subjectification which proposed that the subject only comes into being through language and that this process coincides with and is dependent upon the self being contrasted with what is Other. Fundamentally, he proposes that '[m]an speaks,... but it is because the symbol has made him man' (Lacan 1977: 65). When Lacan argues that words or symbols 'envelope the life of the man in a network so total ... that they bring to his birth ... the shape of his destiny' (68), he reinforces the argument, developed above, that our identities are created by the imposition of arbitrary and hierarchical significations. He adds a different dimension to this, however, because he deals directly with the creation of identities and devises a framework within which the original coming into subjecthood of the child can be understood.

According to Lacan, the subject comes into being at the stage when the child first recognises that it is a separate entity. He refers to this as "the mirror phase", occurring at the time when the child, at around six months of age, realises that the image in the mirror is his or her image, and that, therefore, he or she is separate from all other people. This coincides, Lacan argues, with the child's initiation into the world of language, the symbolic order, and it is in this way that language is seen to be connected to the creation of the subject against a background of otherness (Rose 2000: 52-53).
What is important about the mirror stage is that the child comes to recognise itself in something that is other to it, in a reflection outside of itself. This means that the image it comes to call "I" or "myself" contains, and depends upon, what is not itself. This otherness is recognised in the difference between what the child experiences as a fragmented, uncontrolled body and the close unity of the image with which it is faced as the "self" (Hendricks and Oliver 1999: 24).

From that time onwards, Lacan argues, the subject holds tightly onto his or her desire for unity and, through language, attempts to create a secure space of identity. This attempt to achieve unity through language is highly precarious because, as Saussure has revealed, language is arbitrary and words only have meaning in contrast with what they are not.

In fact, this image of language as a system of communication is one of the ruses of the symbolic order, its perpetual offering of a stable meaning that perpetually eludes us. Language is an unstable and obscure system, offering us identities and simultaneously drawing them away from us. It seems to offer us imaginary individual completion, while entangling us in a shared symbolic order (Mansfield: 2000 47).

Mansfield's point takes us to postmodern notions relating to the decentring of the self and the slippage of meaning in language, both of which will be dealt with later in the chapter. What is important for now is that, because language and, accordingly, the subject, are articulated through difference, the existence of the Other is a vital determinant of identity.

Lacan refers to the self in relation to "the other" in two different ways. The first is the other (with a lower-case "o") which is representative of the image that the child sees in the mirror. This "other" is part of the self, but at the same time separate from it, bringing with it the sense of self to the individual at the same time as fragmenting it. The Other (with a capital "O") is used by Lacan to refer to those who are "not-me", those others who provide the contrast against which we can define ourselves (Lazar 2001: 285). Yet, while Lacan believes that the subject desires to merge with the Other to return to its original, pre-lingual sense of stability and security, my proposition is that, to gain this sense of unity, the subject responds in such a way as to spurn the Other. For, while we are socialised to affiliate with what Mead (1962 [1934]: 56) refers to as the 'generalised other', all that which is outside a comfortable structuring of identity is seen as threatening and undesirable, and it is through language, built on binary oppositions, that the subject creates a safe space to dwell in opposition to that which lives outside the norm.

Butler (1997a) points to the importance of language in constructing identity when she argues that '[t]he subject is called a name, but "who" the subject is depends as much on the names that he or she is never called: the possibilities for linguistic life are both inaugurated and foreclosed through the name' (Butler 1997a: 41). A symbolic system, such as the English language, which
achieves its meanings through the construction of binary oppositions can only really identify subjects of discourse by locating them as members or non-members of culturally desirable categories. This is why disability cannot be defined as multiple variations of an acceptable identity. It can only be seen as not-able, not-normal, not-enfranchised, that is, unacceptably different, antithetical to the norm. Yet, it is more than individual words which frame the derogatory concepts which are associated with Otherness. Oppression is born and takes residence in the patterns and rhythms of language in the larger sense of its signification.

Semantics and Disability Discourse

Racist language is significant only within a context that sanctions wide varieties of disparate treatment of members of races deemed lesser, including social and economic isolation, harassment, violence, and even genocide. These practices are the core - the threat and the reality - of racism. Without their cultural and material "back-up," words like the derogatory terms we are considering would not have force they do (Tirrell 1999: 45).

Words have no proper meaning, because no meaning can be said to 'belong' to them; and they do not possess any meaning in themselves, because it is discourse, taken as a whole, that carries the meaning, itself an undivided whole (Ricoeur 1978: 77).

While it is vital to understand language from a semiotic perspective, that is, to discover how meaning is created through individual signs, this is only one side of the equation. What is signified by a particular signifier or, in other words, which concept is attached to a certain word in a particular context, is reliant on more than the image associated with that word. It depends on the context in which the word is used. Ricoeur (1978) draws on Beneventiste to argue that this relies on an understanding of semantics.

The sign is the unit of semiotics while the sentence is the unit of semantics. As these units belong to different orders, semiotics and semantics hold sway over different arenas and take on restricted meanings. To say with de Saussure that language is a system of signs is to characterise language in just one of its aspects and not in its total reality (68).

Words alone have limited power. It is only in combination that they develop the complex, often subtle meanings through which they wield their real influence. ‘The sentence is realised in words, but the words are not simply segments of it. A sentence constitutes a whole which is not reducible to the sum of its parts; the meaning inherent in this whole is distributed over the ensemble of its constituents’ (Benveniste as quoted in Ricoeur 1978: 66).

Merleau Ponty (1964a) points to the deficiency that exists in an approach which only focuses on individual signs. Like Ricoeur, he argues that ‘[t]he reason why a language finally intends to say and does say something is not that each sign is the vehicle for a signification which allegedly belongs to it, but that all the signs together allude to a signification which is always in abeyance
when they are considered singly' (Merleau-Ponty 1964a: 88). He believes that the sign 'does not so much express a meaning as mark a divergence of meaning between itself and other signs' and that, because signs are only definable in contrast to what they are not, they can only have true meaning in combination (39). 'As far as language is concerned, it is the lateral relation of one sign to another which makes each of them significant, so that meaning appears only at the intersection of and as it were in the interval between words' (42).

Going one step further into a political analysis of language, Lyotard (1988) argues that semantic meaning is encapsulated in what he calls 'phrase regimens' (28-29). For Lyotard, as Hammer (1997) argues, '[t]he primary unit of discourse is the phrase which is constituted by a set of rules called "regimens" which define the properties and uses of the phrase' (482). Lyotard, thus, believes in the primacy of word chains for the creation of meaning, and he extends the analysis to incorporate different kinds of phrase structures such as those which are based on 'reasoning, knowing, describing, recounting, questioning, showing, ordering, etc' and which create meanings in different ways (ibid.). He also argues that the way phrases are linked is vital to their signification and that it is the combination of "phrase regimens" and "linkages" that determines the power of the speaker in relation to what can be said and what cannot. Haber (1994) argues, in line with Lyotard, that the limitations in the number of possibilities for speech through such structures results in 'the silencing of the voice of the Other; the Other becomes a plaintiff divested of the means to argue and becomes, on that account, a victim' (20).

Semantics is vital to the study of language and identity because it links the individual symbols which affect our labelling processes with the discourses which inform them. It is certainly significant that single words express very strong ideas about what is desirable and undesirable in a particular culture. The words "disabled", "cripple", "spastic", "invalid", "weak" and "abnormal" evoke very intense, very negative images. However, it is the framework within which these words are embedded, the sentences, the discourses which inform their use and their possibilities, which bring us to the heart of the connection between language and power. The word "disability", for example, conjures up the images it does because it mediates between the recipient of the word and the larger discourse within which disability is framed. This discourse includes medical knowledge, media imagery, sociological discourse, the education syllabus and political programmes, to name just a few sites of knowledge creation and/or dissemination. Therefore we need to understand not only how language functions symbolically, but also how these symbols are tied, through discourse, to systems of power.

Danaher et al. (1996) argue that '[f]or Foucault, one of the most significant forces shaping our experiences is language' (31). This statement needs some qualification. Foucault's (1970; 1972) early, "archaeological" work is strongly in favour of an approach which focuses on language, but even then he was careful to always speak of language in the context of discourse. Later, in his genealogical investigations, he often wrote scathingly of the semiotic approach because it
lacked teeth, that is, it ignored or did not explore the connection between language and power. Foucault (1980g) wanted it to be known that he had moved beyond a sanitised exploration of language and had entered the field, ‘violent, bloody and lethal’, of power relations.

Here I believe one's point of reference should not be to the great model of language (langue) and signs, but to that of war and battle... Neither the dialectic, as logic of contradictions, nor semiotics, as the structure of communication, can account for the intrinsic intelligibility of conflicts. 'Dialectic' is a way of evading the always open and hazardous reality of conflict by reducing it to a Hegelian skeleton, and 'semiology' is a way of avoiding its violent, bloody and lethal character by reducing it to the calm Platonic form of language and dialogue (114).

This does not entail, however, a rejection of the importance of language as a whole. Discourse is, after all, both built from language and responsible for the tone that it takes. Indeed, it is impossible to think about discourse without taking into account the language that forms it, a fact that Foucault himself observes:

Discourse - the mere fact of speaking, of employing words, of using the words of others (even if it means returning them), words that the others understand and accept (and, possibly, return from their side) - this fact in itself is a force (Foucault as quoted by Davidson (1997): 4).

In Hall’s (1997) view, '[t]he main point to get hold of here is the way discourse, representation, knowledge and ' truth ' are radically historicised by Foucault, in contrast to the rather ahistorical tendency in semiotics' (46). And in placing language in its historical context, Foucault creates a space within which other possibilities can be imagined.

For Foucault, discourses are ‘practices that systematically form the objects of which they speak... Discourses are not about objects; they do not identify objects, they constitute them and in the practice of doing so conceal their own intervention’ (Foucault 1972: 49). In this sense, discourses are ways of thinking which have been institutionalised through culturally approved apparatuses of power. Hall (1997) states that Foucault sees discourse as 'a group of statements which provide a language for talking about - a way of representing the knowledge about - a particular topic in a particular historical moment... Discourse is about the production of knowledge through language. But... since all social practices entail meaning, and meanings shape and influence what we do - our conduct - all practices have a discursive aspect' (44).

When discussing the relationship that exists between his various genealogical projects, Foucault (1982) declares that his objective 'has been to create a history of the different modes by which, in our culture, human beings are made subjects' (208). He achieves this by exploring the three axes of subjectification: truth, power and ethics, and argues that he wishes 'to know
how the reflexivity of the subject and discourse are linked' (Foucault 1988g: 38). The social
nexus which connects discourse and the subject is fundamental to both Madness and
Civilisation and The History of Sexuality.

Regarding madness, my problem was to find out how the question of madness could be
made to operate in terms of discourses of truth, that is to say, discourses having the
status and function of true discourses. In the West that means scientific discourse. That
was also the angle from which I wanted to approach the question of sexuality (Foucault
1980h: 210).

Indeed, it would not be an overstatement to suggest that Foucault believed that identities such
as the madman, the criminal, the homosexual, the hysterical woman and, in fact, all identities as
we know them, would not exist outside of discourse. 'Foucault argues that since we only have a
knowledge of things if they have a meaning, it is discourse - not the things-in-themselves -
which produces knowledge. Subjects like 'madness', 'punishment' and 'sexuality' only exist
meaningfully within the discourses about them' (Hall 1997: 45-46).

The same applies to disability. Disability is created through a range of discourses which interact
to produce the disabled identity. In an elegant and incisive study of the connections between
disability and discourse in Australia, Price (1995) draws on Foucault's belief 'that in every
society the production of discourse is at once controlled, selected, organised and redistributed
by a certain number of procedures' (7). Three of the procedures which Price argues are relevant
to the discursive construction of disability are 'prohibitions', 'truths' and 'rules'. According to
Price, prohibitions are enacted through impositions which limit how disability is to be talked
about. What is allowed and what is prohibited in and through disability discourse depends on
the 'truths' that have evolved via the interaction of the human sciences and policy rhetoric, and
the 'rules' which govern who can gain entry to the discourse.

So it is that the individual is subject to a number of discursive practices. A multiplicity of
discourses occur, and it is these groups of knowledge or understandings which sanction
particular social practices. These discursive practices are the nexus of society. In the
area of disability, service providers, consumers, and policy text are all constructed
through these discursive practices. They both contribute to, and yet are determined by,
the discourses which circumscribe and delimit their social practices (Price 1995: 9).

Madden and Hogan (1997), authors of the government publication, The Definition of Disability in
Australia: Moving Towards National Consistency, focus on the evolution of terminology used to
describe disability within government programmes. They do not write from a critical perspective.
Rather, their analysis follows the prescriptions called for within the discourses they explore. Yet,
this makes their statements even more revealing in relation to how power works through
language, concealed by "truth". They state that '[t]erminology has played a crucial role in
achieving changed policy and perceptions in the disability field. Good terminology unearths and crystallises basic concepts. Ideally it is also stable and consistent enough to help people communicate' (65). This, I would argue, is an innocent description of how language is manoeuvred to serve particular purposes. Thus, when Madden & Hogan (1997) state that 'definitions at best reflect "true" underlying concepts and are consistent with current terminology' (op cit.) they refer to a "truth" created through discourse. Most revealing of all is their closing statement: 'terminology [is] the flag bearer of vision and sometimes change' (ibid). One need only ask, whose vision and what kind of change?

Governmental terminology creates images of disability through such symbolic locations as eligibility criteria which define disability as the inability to work, disabled parking signs which reduce disability to the notion of wheelchairs, and "support services" which emphasise dependence and inertia. The language and the images produced through the discourse which informs and is created by political programmes are, however, only one strand in the complex web of discourse which produces the disabled identity. Medical and social science knowledge, educational paradigms and cultural images disseminated through literature and the communications media are likewise involved in the creation of disability and are thus a function of what Foucault (1977c) refers to as the 'multiplicity of discursive elements that come into play' in creating subjectivity (100). None of the discourses which are embedded in these areas of knowledge production can be distinctly separated from any of the others as they all interact within an overarching framework or rationality, but it is possible to tease out their individual contributions to the formation of the disabled subject so as to 'reconstruct... the things said and those concealed, the enunciations required and those forbidden' in the reification of disability (ibid).

Chief among these contributions is medical discourse. Because it is based on a humanist model of personhood, it focuses on the individual and not the social structure and, therefore, leads to the view that disability is a personal tragedy rather than a socially created problem. Sullivan and Munford (1998) elaborate:

A central technology of power that operates to create disabled people is the medical discourse on impairment. Discourse functions to regulate the way individuals think about the world and live their lives. Lived practices are, in turn, regulated through ideas, language, institutional behaviour, rituals and social relationships. In this sense... [m]edical discourse determines the ways in which disabled people are perceived and socially located (187).

The perceptions that are developed around disability and the disabled identity through medical discourse involve not only the assumption that the person who becomes disabled is physically damaged, but that they become socially unacceptable as well. Hughes (2000) expresses it thus: '[The medical] model is far from socially benign, since for disabled people, it is based on the
disabling extrapolation that bio-physical 'maladaptation' - to use the ubiquitous evolutionary terminology - leads to social maladaptation' (555).

In a study which focuses on the rehabilitation of people who have had limbs amputated, Gallagher and McLachlan (1999) refer to 'psychological and social adjustment problems' such as 'shock, denial, grief [and] depression' which must be addressed by the disabled person in 'learning to cope with their loss' (118). This study is typical of the prevailing attitudes towards disability which exist within the health and social sciences and emphasise individual psychological change in terms of "coping", "adjustment", and "adaptation". Rather than focus on why disability causes such shock, grief and depression, the emphasis is on what McNamee (1996) refers to as 'identity adjustment' which relies on teaching the disabled person to accept their oppressive identifications (145). This attitude is rife throughout the literature informing psychology, psychotherapy, sociology, medicine and rehabilitation. Barnes, Mercer and Shakespeare (1999) argue that, due to its definition within medical discourse, 'the "disability" takes over the individual's identity and constrains "unrealistic" hopes and ambitions. Those with a perceived impairment accept being defined as not "normal" and in some ways "defective"... [and thus] are socialised into a traditional disabled role and identity, and expected to submit to professional intervention in order to facilitate their adjustment to their "personal tragedy" (25).

School-based pedagogic discourse is another area where pervasive views of disability are developed and disseminated. Both the ways in which mainstream schools present the concept of disability to their able-bodied students and the methods by which special schools operate to socialise children into disabled roles influence how disability is perceived and experienced. Clarke et al. (1998), in their exploration of special education discourse, argue that it is based on psychological and medical perspectives of disability and thus focuses on individual deficit. Moreover, Saini (2001) in her semiotic study of mothers’ wish to place their children in non-segregated schools, shows how the exclusion inherent in special education facilitates the creation of subordinate identities. In parallel to this, Sleeter and Grant (1991) conclude that disabled people are either absent from or symbolised as powerless within a range of social studies, maths, science and English mainstream text books. They argue that:

In this way, curriculum usually serves as a means of social control. It legitimates existing social relations and the status of those who dominate, and it does so in a way that implies that there are no alternative versions of the world, and that the interpretation being taught in school is, indeed, undisputed fact. Knowledge helps shape power and social activity (or lack of it) (80).

Discourse evolving within and dispersed throughout the educational environment is perhaps one of the most influential locations for the linking of power to subjectivity because it is a major site of socialisation for the young (Kenway 1995: 132). The idea that disability is an inferior and pitiable condition is introduced at a very early stage to both disabled and non-disabled children.
The discourses of medicine, social science and education certainly provide a very fertile environment for the propagation of demeaning representations of disability. Yet, while in earlier times these discourses were introduced into the lives of disabled individuals through either direct contact with medical professionals or the common-sense understandings which derived from medical and scientific knowledge, over the past few decades a myriad of cultural forms have emerged through the rapid growth in communications media and multiplied the sites for identity creation and reinforcement. While the novel has been producing questionable images of disability for centuries, the endless repetition of images made possible by electronic media sources has increased and intensified the impact of the technologies of subjectification. Karpf (1988), in her book *Doctoring the Media*, devotes a chapter to what she refers to as ‘crippling images’, those images which marginalise the disabled identity via popular culture. The kind of images which can be considered "crippling" include 'the media fondness for cure stories; the role of charity appeals; the invisibility of disabled people on television; the stereotyped portrayal of disabled characters in screen drama; the under employment of disabled people in broadcasting' (Davis 1997a: 23).

The discourses discussed here bind the subjective fate of those who become disabled in a knot so tight and yet so elusive that it is extremely difficult to loosen its grip. The resistance of these bonds to any interference is a function of what Marx called "ideology" and Gramsci "hegemony" where both concepts allude to the invisible nature of the shackle and thus the complicity of the subject. Langman (1998) discusses how this complicity is achieved in his exploration of the connections between hegemony, identity and subjectivity.

With language and reflexivity, the colonisation of subjectivity has the insinuated elite interests within the person... Thus hegemony secures 'willing assent' in so far as it is secured by socially based desires and mediated through identities. The constitution of such identities serves to colonise agency in such ways that the continual enactment of daily routines, interactions and the logics of understanding that the micro-social level of reproduce the social structure (188).

Foucault's rejection of the humanist belief in totalising power structures made him resistant to such concepts as hegemony and ideology, but, as Sarup (1996) points out, in developing the concept of discourse, he was able to address the 'problems with the ideology/truth opposition' and thus 'short circuit [these] epistemological problems' (69). And, ultimately, I believe that this has made possible an understanding of how identity, as a concept created through language, has come to form an invisible conduit between power and subjectivity.
Spoiled Identities and Muted Voices

The first and most important thing to remember about discussions of language and disability is that they arise because disabled people experience discrimination daily and are denied the same rights and opportunities as the rest of the population. Apart from the fact that words can be deeply hurtful to disabled individuals, they have power and are used extensively to justify oppression (Barnes 1993: 8).

I now wish to focus more specifically on the implications of my theoretical discussion in exploring how language stands to affect disabled people in their daily lives. As has already been discussed, language can impact on the way that disabled people experience the world in two ways: “through macro-linguistic strategies, involving whole narratives [or discourses], or through micro-linguistic practices, in which short phrases and even single words carry ideological significance” (Priestley 1999: 93). In unravelling this, I focus on the ways that individual words stigmatise and discourses silence. On a semiotic level, words which have negative connotations are used to label and, consequently, stigmatise disabled people. Alongside this, discourses put signs in their political contexts, delimit what can and cannot be said and, in so doing, privilege the norm and silence the margins. Both these processes of stigmatisation and silencing, which are, of course, not so neatly separable as this might suggest, need to be understood to properly appreciate the production of the inferior status accorded disabled people.

Goffman’s (1963) *Stigma: Notes on the Management of Spoiled Identity* serves to illuminate, on several different levels, our understanding of the creation of the disabled identity through the stigmatising properties of language. Goffman was a brilliant observer of social interaction and his research into the effects of disability on the inner worlds and outward behaviour of disabled people, as well as the reactions of non-disabled individuals to impairment, still provides a great deal of insight into how stigma operates in society. At the same time, he also represents a micro-sociological viewpoint which focuses on individual perceptions but not their structural causes, leading to the belief, in keeping with the medical model, that disabled people must deal with their stigmatisation by learning to cope with it, not by challenging its structural origins. And, lastly, he speaks in the language of the culture at large without being the least bit critical of it, for example, when he uses such terms as "affliction," "victim," and "cripple," and introduces people as "cases". In this way, Goffman educates us in more ways than one, because, while he maps the existence and performance of stigma with great precision, he also enunciates with complete innocence and, therefore, equal precision, the attitudes which propagate it.

Goffman (1963) defines stigma as ‘the situation of the individual who is disqualified from full social acceptance’ (9) and states that people who are stigmatised are seen as ‘not quite human’ and ‘reduced in our minds from a whole and usual person to a tainted, discounted one’ (5). He argues that, fundamental to learning to live with disability or other forms of stigmatisation is learning the normal point of view and learning that he is disqualified according to it. Presumably
the next phase consists of his learning to cope with the way others treat the kind of person he can be shown to be' (101). From this view, disability not only involves the production of an extremely negative identity, it also demands that the disabled person take full responsibility for defusing it, as when Goffman suggests:

Normals mean no harm; when they do, it is because they don't know better. They should therefore be tactfully helped to act nicely. Slights, snubs and untactful remarks should not be answered in kind. Either no notice should be taken or the stigmatised individual should make an effort at sympathetic re-education of the normal showing him, point for point, quietly and with delicacy, that in spite of appearances the stigmatised individual is, fundamentally, a fully human being (146).

According to this view, a view which remains almost unchallenged even today, the existence of stigma is unavoidable and proceeds naturally from the possession of an identity which is considered unacceptably different.

Peters (1999) makes the connection between stigma and discriminatory language and argues that 'people with disabilities experience invasion of their disability identity through the practices of labelling and hegemonic language usage detrimental to their images' (103). The primary mechanism whereby this labelling is achieved is through the creation of stereotypical identities. In this way, key words, such as "cripple", "disabled" or "handicapped", are attached to a set of images which, regardless of whether they in fact describe the person in question, are assumed to do so because they are associated with disabled people in general. In semiotic terms, the signifier, "disabled," becomes attached to a range of significatory concepts (signifieds) such as weak, passive, dependent, unintelligent, worthless and problematic, so that when the word is spoken, a negative, even if partially subconscious, feeling is evoked.

Stigma as a form of negative stereotyping has a way of neutralising positive qualities and undermining the identity of stigmatised individuals This kind of social categorisation has also been described by one sociologist as a "discordance with personal attributes". Thus, many stigmatised people are not expected to be intelligent, attractive, or upper class (Coleman 1997: 221 -222).

It is this "discordance with personal attributes" which can be the most frightening factor in the experience of stigmatisation, because it creates an existential crisis which often can only be resolved by internalising the view of the oppressor.

Quasthoff (1989) comments that stereotypes are ‘emotionally evaluative’, are ‘characterised by persistence and rigidity’ and are ‘resistant to change in societies as well as in individuals' (182). They are, thus, very powerful political tools in their concise and incisive ability to subjectify. They both emanate from and contribute to the process of normalisation through the construction of
binary oppositions, with the norm represented by "stereotypical" images of activity, independence and achievement. The threat wielded by the negative stereotype can be a strong deterrent against bucking the system and those who, like disabled people, cannot avoid becoming Other become exemplary, through their stereotypical representation, of what not to be.

Stereotyping, in other words, is part of the maintenance of the social and symbolic order. It sets up a symbolic frontier between the 'normal' and the 'deviant', the 'normal' and the 'pathological', the 'acceptable' and the 'unacceptable', what 'belongs' and what does not or is 'Other', between 'insiders' and 'outsiders', Us and Them. It facilitates the 'binding' or bonding together of all of Us who are 'normal' into one 'imagined community'; and it sends into symbolic exile all of Them - 'the Others' - us who are in some way different - 'beyond the pale' (Hall 1997: 258).

In this way, and, as Hall (op. cit.) argues '[s]tereotyping is a key element in [the] exercise of symbolic violence' (259). This symbolic violence operates nowhere more clearly than in the fact that stereotyping results in the disabled person being allocated a 'master status' (Becker 1963: 32-33) or a label of 'primary potency' (Singh 1999: 88). In this way, the diversity which characterises any group of disabled people slips below the plane of sight. Robert Murphy (1990) whose book The Body Silent is a testament to the systematic dismantling of a disabled person's identity, writes that '[s]tigmatization is less a by-product of disability than its substance. The greatest impediment to a person's taking full part in this society are not his physical flaws, but rather the tissue of myths, fears, and misunderstandings that society attaches to them' (113).

But, it is once again necessary to go back to our fundamental question of how this process of "naming," of being allocated an identity, is tied to discourse. One fruitful way of approaching this is through the concept of "performativity." The term "performative" was originally coined by Austin (1962: 6-7) to describe words which perform an action by way of their utterance and has been used extensively by theorists such as Bourdieu, Derrida and Butler to demonstrate how subjects are formed through the ceaseless repetition of their identification through language and the performance of their identities. A clear example of a performative phrase is the announcement, upon the birth of a baby: "It's a girl!" The mere uttering of these words imposes an identity upon the child that will impact on her for the rest of her life. I argue that "disability" has a similarly performative effect, because, by naming the person "disabled", he or she inherits all the connotations that have been accorded disability through the discourses discussed earlier. In other words, being called "disabled" effectively disables and, in so doing, is a term which performs an action. These words are so effective at concealing their powers of institution because they appear to be what Austin referred to as "constative", words which merely describe an existing reality. But, as Bourdieu (1991b) argues, these terms are actually 'prescriptive' in
that they create what they pretend only to mirror (134). 'Become what you are: that is the principle behind the performative magic of all acts of institution' (Bourdieu 1991: 122).

Butler (1990) defines performativity as 'the reiterative power of discourse to produce the phenomena that it regulates and constrains' (33). It is through the repetition of words and associated images mediated by discourse that disability takes on its current meaning. Disability and its counterpoint "able-bodiedness" are performed through a variety of ritualised techniques embedded in language which come to define them as instances of privileged or marginalised identity. Derrida (1977) points out that the reiteration of an identity does not rely on having something stable or "real" to copy from, a certified original, but depends, alternately, on having a sanctioned pattern of repetition associated with its performance, 'a "coded" or iterable utterance...identifiable in some way as a "citation"' (18).

If a performative provisionally succeeds (and I will suggest that "success " is always and only provisional), then it is not because an intention successfully governs the action of speech, but only because that action echoes prior actions, and accumulates the force of authority through the repetition or citation of a prior, authoritative set of practices. What this means, then, is that a performative "works" to the extent that it draws on and covers over the constitutive conventions by which it is mobilised (italics original) (Butler 1993: 227).

In relation to disability, this means that there is no original form or example of disability to copy from: there is always only the copy which has been circulated under the guise of an essential quality. This is how disability becomes a concept which is taken for granted as a physically governed, rather than a socially constituted, reality. Drawing from Baudrillard (1983) it is then possible to view disability as a 'simulacrum', a replication of a representation or an image which has been constructed to give the category "normal" substance (4).

Discourse silences disabled people in many ways. It leaves them with no language with which to express themselves, it invalidates their narratives and, therefore, their subjective realities, and it renders them invisible. When Foucault (1988g) was asked whether he had any intention of trying to rehabilitate the Other through raising the profile of subjugated language, he replied: 'How can the truth of the sick subject ever be told?' (29). Discourse, in creating the space for subject formation by marking the boundaries of exclusion, leaves us with silent subjects who have no way of telling their stories and articulating their subjecthood or lack of it. Thus, the possibilities for how disabled people will be able to see themselves and their situations are defined by what Sapir refers to as 'the tyrannical hold that linguistic form has upon our orientation in the world' (as quoted in Muhlhausler and Harre 1990: 4).
Yet, even for those who can see beyond the dominant rationality to question their oppression, the opportunities for them to articulate their objections are strictly limited within the framework which governs acceptable patterns of thought and speech. People who question the dominant ideology often appear not to make sense; what they say won’t sound logical to anyone who holds that ideology. In extreme cases, people who ask such questions may even appear mad. So while it is possible to question the dominant culture there is often a price to be paid for doing so (Jones and Wareing 1999: 34).

Young (1990) argues similarly that when people who are classed as Other attempt to voice any objections to their identification they are ‘met with denial and powerful gestures of silencing, which can make oppressed people feel slightly crazy’ (134). This resonates with Foucault’s (1988c) discussion of madness in terms of ‘forbidden speech’ (179). In this way, madness operates as a punishment and a deterrent, a warning to those who might attempt to speak outside of acceptable discourse.

Arguably, the worst of all the ways one can be silenced is to be ignored altogether, to be rendered invisible. ‘Indeed, one can be interpellated, put in place, given a place through silence, through not being addressed, and this becomes painfully clear when we find ourselves preferring the occasion of being derogated to the one of not being addressed at all’ (Butler 1997a: 27). Witkin (1998) writes of the extreme kind of invisibility which is experienced by those with ‘severe or multiple disabilities’ who ‘do not participate in the mainstream of community life’ (294). Yet, even more insidious in some ways because of its subtlety is the invisibility which accompanies being identified as disabled ahead of anything else, of being patronised, ignored, devalued, and rejected, and of not being heard no matter how hard one tries to be understood.

Those silenced through discourse have been variously described in terms of "abject bodies" (Butler 1990), "subaltern voices" (Spivak 1988), "the differend" (Lyotard 1988) and, as already discussed at length, "subjugated knowledges" (Foucault 1980d: 82). Each of these terms refers to their exclusion from language and explores this silencing in the context of dominant discourses. Butler (1990) argues that “normative injunctions” constitute the privileged subject and result in the abjection of those constructed outside the domain of acceptability (144-149) and suggests that “[t]he abjection of certain kinds of bodies, their inadmissibility to codes of intelligibility, does make itself known in policy and politics, and to live as such a body in the world is to live in the shadowy regions of ontology’ (Butler as quoted in Meijer and Prins 1998: 280). It is this ‘shadowy region of ontology’ that Mutua (2001) refers to when he writes of the invisibility of disabled people in Kenya, referring to them as ‘nameless shadows’ (107).

Similarly, Spivak’s term “subaltern voices” refers to the suppression of the ability to express one’s marginalisation, but this time from a postcolonial perspective where the oppressed in
question are those who have been subjected to the cultural imperialism of the colonial oppressor. Spivak (1988) poses the question in her article of the same name: 'Can the subaltern speak?' to which her answer is a resounding "no!" Davidson (2001) emphasises that Spivak 'ground[s] her argument in a consideration of the issue of sati - widow burning - in colonial India, maintaining that subaltern women's voices are completely absent in extant records because colonial and indigenous manipulation of female agency silenced them' and goes on to argue that, for Spivak, 'there is no possibility of the subaltern ever coming to voice or of anyone else ever speaking for her' (Davidson 2001: 170).

In developing the notion of the differend, Lyotard (1988) constructs a new way of understanding how silencing occurs. As discussed above, the numbers and kinds of "phrase regimens" available limits what can be said and results in the creation of the "differend", an excess of meaning which cannot be expressed. Lyotard (1988) argues that this excess results in 'the case where the plaintiff is divested of the means to argue and becomes for that reason a victim' (9).

In the differend, something asks to be put into phrases and suffers from the injustice of not being able to be instantly put into phrases. This is when human beings who thought they could use language as an instrument of communication learned through a feeling of pain which accompanied silence (and of pleasure which accompanied the invention of a new vision), that they are surrounded by language... to recognise that what remains to be phrased exceeds what they can presently phrase, and that they must be allowed to institute idioms which may not yet exist (10).

Lyotard, like Spivak, gives a way of understanding the process of muting that accompanies subjectification, but suggests that there may be ways of creating new language, new "idioms", which constitute the ultimate hope for building a resistance against the hegemonic use of language. In what remains of this chapter, I will discuss how the raising of the subaltern voices of disabled people is currently occurring through the development of new idioms through slippage and metaphor, the inherent difficulties in doing so, and how these can be overcome.

**Challenging Disabling Discourse: Finding a Voice**

Coining a new word is more like driving a wedge into a crack in a wall than putting a torch on a previously unilluminated part of the stone work (Griffiths 1995: 169).

Tomorrow I am going to re-write the English language
I will discard all those striving ambulist metaphors
Of power and success
And construct new images to describe my strength
My new, different strength.
Then I won't have to feel dependent
Because I can't stand on my own two feet
And I will refuse to feel a failure
When I don't stay one step ahead.
I won't feel inadequate if I can't
Stand up for myself
Or illogical when I don't
Take it one step at a time.

I will make them understand that it is a very male way
To describe the world
All this walking tall
And making great strides.

Yes, tomorrow I am going to re-write the English Language,
Creating the world in my own image.
Mine will be a gentler, more womanly way
To describe my progress.
I will wheel, cover and encircle
Somehow I will learn to say it all. Lois Keith 1994: 57

As I have attempted to demonstrate, language is constructed with the purpose of representing and perpetuating certain systems of meaning and it is from within these conceptual structures or discourses that the disabled person has been molded. Therefore, in line with Kristeva (1986), I argue that our greatest chance for being able to reform the cultural landscape from which the concept of disability has been carved lies within the theoretical project of ‘reshaping the status of meaning within social exchanges’ (32). This linguistic reform can be approached on a variety of levels: that of the individual word, label or symbol; at the semantic level; or at the level of discourse. I believe that, although each of these approaches are vital for the elevation of the social status and the subjective liberation of disabled people, they must be taken in combination because each comprise an essential layer in the overall system of meaning creation. In philosophical terms, each factor is necessary but not sufficient for the development of positive identifications.

The political significance of language as a tool for resistance has been well documented in studies of nationalism and national identity, particularly in relation to struggles for independence (Heywood 1992: 136-142). For example, prior to the incidence of Western imperialism in the East Indies, the peoples who inhabited this extensive network of islands possessed no cultural bonds and their languages were diverse. However, in forming together as Indonesians to overcome colonial rule, their adoption of bazaar Malay as their common language ‘not only allowed people to formulate concepts of nationalism, but became one of the symbols of national vigour’ (Mackerras 1994: 519). In keeping with this, Oliver (1989b) suggests that ‘[p]idgin, dialect, slang, anti-sexist and anti-racist language and sign language are not, therefore, quaint and archaic forms of language use but forms of cultural resistance’ (37). To succeed in
achieving cultural resistance through the creation of new language, however, requires an understanding of the obstacles inherent in the structure of language itself.

The simplest form of resistance which has been developed by disabled people to challenge their linguistic subjugation involves what I call an “elementary semiotic approach”, focused on challenging negative labels. Put simply, this approach derives from the notion that certain words used to describe disability have taken on derogatory connotations and therefore need to be replaced with terms which evoke a more positive image. Words such as ‘freak, gimp, spastic, spaz, cripple, cretin, handicapped, monster, mongoloid, invalid, idiot, retard, defective, dumb, mute,’ are extremely negative labels which should be resisted at all costs (Russell 1998: 14). The problem, however, with simply replacing them with more politically correct terms, like "disabled", "impaired", "developmentally delayed", "intellectually disabled", and "hearing impaired"¹, is that the assignment of new labels does not address the oppressive concepts which gave these words their negative connotations in the first place. As Barnes (1992) points out, ‘there’s nothing inherently wrong with these words..."cripple," "spastic," and "idiot"…it is simply that their meaning has been substantially devalued by societal perceptions of disabled people’. And, unfortunately, the new words developed to describe impairments and the people who bear them have quickly become tainted with the associations carried by the old ones.

Even worse, Marks (1999) argues, is that the introduction of the new terminology sometimes actually serves to mask some of the more deeply oppressive realities that frame disabled people's lives. She discusses how the adoption of terms such as "special needs" for the resources required by disabled people to function independently, and "self-advocate" for people who have intellectual impairments can conceal the very real problems faced by disabled people given their implicit suggestion that equity is being realised. In essence, then, the elementary semiotic approach is doomed to failure because the introduction of new words on their own cannot dismantle deeply rooted discrimination. And the reason for this is explained by Saussure himself in his chess analogy, mentioned earlier. The swapping of a rook for a piece of a different shape does not change anything if this new piece operates like a rook. It is the rules of the game which must change for the new piece to be capable of new moves.

Furthermore, many of the new words developed to describe disabled people have not been chosen by disabled people themselves and are not seen by them to reflect their identities or political desires. Words such as "physically challenged," "able disabled," "handicapable," "special people/children," "differently abled," and "people with differing abilities" are all attempts to raise the status of disabled people by providing more positive sounding labels but they have been rejected by disabled people as undesirable. Linton (1998) refers to these kinds of terms as 'nice words.' They are rarely used by disabled activists and scholars (except with palpable irony). Instead, in the view of many, they convey the boosterism and do-gooder mentality
endemic to the paternalistic agencies that control many disabled people's lives' (Linton 1998: 14). Gilson, Tusler and Gill (1997) also speak out strongly against the use of such terms when they argue that 'these euphemisms have the effect of depoliticising our own terminology and devaluing our own view of ourselves as disabled people' (9).

Disabled people who are working for change, both activists and scholars, have attempted to address linguistic discrimination on a deeper level. In this respect they have investigated the ways in which apparently technical or neutral language inflicts negative connotations in a widely pervasive but less obvious way. Medical definitions which ascribe disabled people the labels of "patients" and "cases" are allied to descriptors such as "afflicted by," "suffering from," "stricken with," and "a victim of," all of which infer weakness, lack of agency, martyrdom and/or individual responsibility. Also detrimental to the image of disabled people is the use of adjectives as nouns, as in "the deaf," "the blind," "the mentally retarded," "the handicapped," "the disabled," "the developmentally disabled" and "the chronically ill".

All of these adjectives used as abstract nouns contribute to the process of stigmatization by reinforcing the tendency to "see" persons with disabilities only in terms of those disabilities. These labels rivet attention on what is usually the most visible or apparent characteristic of the person. They obscure all other characteristics behind that one and swallow up the social identity of the individual within that restrictive category (Dajani 2001: 198-199).

The same problems apply to the habit of referring to people in terms of their illness or disability. To refer to someone as a paraplegic, an epileptic or an arthritic is not so different from calling them a cripple as it paints the disability as the primary label of identification, in effect 'engulfing a person's social identity' (ibid.). Barnes (1992) points out that '[w]here it is absolutely necessary to refer to an individual's impairment it is better to say "has epilepsy" or "has arthritis"'. Overall, to attempt to change these discriminatory practices of representation goes beyond the swapping of labels and requires addressing the formation of meaning through semantic structure so that it is possible to dismantle the concepts behind the labels.

The linguistic challenge launched by disability theorists and activists through the social model has involved the twin aim of challenging the oppressive nature of current terminology and revealing how euphemisms mask the very real problems faced by those who are disabled. This has entailed ensuring that 'the terms which have been unquestioningly used come to be critically scrutinised by those so labelled, and are either rejected or "owned" but radically redefined (italics added) (Thomas 1999b: 13). In this way, for example, British disability activists who had begun to demand the development of a socially based definition of disability in the late

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1 Thorick, Roberts and Battistone (2001) object to the term "hearing impaired", pointing out that 'we do not label a Black person "white impaired," and we would not call a man a "female-impaired" person' (191).
1960s to early 1970s, were not impressed by the WHO’s attempt to include social considerations in their definitions through the concept of “handicap” in their international Classification of Impairment, Disability and Handicap (ICIDH). Marks (1999) paraphrases the ICIDH as follows.

‘Impairment’ refers to any loss or abnormality of psychological, physiological or anatomical structure or function. ‘Disability’ is any restriction or lack - resulting from an impairment - of ability to perform an activity in the manner or within the range considered normal for a human being. Finally ‘handicap’ denotes any disadvantage to an individual resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for the individual (54).

Instead, the British activists preferred to build on the principles behind the redefinition of “disability” and “impairment” first articulated by the Union of the Physically Impaired Against Segregation (1976) in their publication, Fundamental Principles of Disability. Here, impairment was defined as ‘[l]acking part or all of a limb, or having a defective limb, organism or mechanism of the body’ and disability as ‘[t]he disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from mainstream social activities’ (3-4). What was revolutionary about this reclassification was that the physical component of “impairment” was separated from the socially imposed component of “disability”, so that it could be recognised that social exclusion was the fundamental issue, not physical limitation or personal tragedy.

More recently, disability rights activists and scholars subscribing to the social model have also criticised the use of the terms “handicapped” and “people with disabilities”. The rejection of “handicapped” is a straightforward one and has been met with universal agreement. ‘Referring to disabled people as “handicapped” stems from the notion that the whole of life is a competition - as in horseracing or in golf - and implies that they will not do well. Also “handicap” has allusions to “cap in hand” and begging. Neither term is acceptable to the disabled community’ (Barnes 1992). However, the expulsion of the signifier “people with disabilities” derives from a more complex argument and has been met with mixed reactions. The original intention behind the use of “people with disabilities” was to challenge the assignment of a ‘master status’ (Becker 1963: 32-3) or a label of ‘primary potency’ (Singh 1999: 88). However, proponents of the social model have largely agreed upon the use of “disabled person” because people cannot “have” a disability under the social model’s definition of the word.² People can have impairments, but

² Barnes (1992) states the full argument against the use of “people with disabilities” as follows:

“Firstly, ‘people with disabilities’ assumes that disability is the property of the individual and not of society. Here the terms ‘disability’ and ‘disabilities’ refers to a medical condition; and ‘person with the disability’ can easily be substituted by ‘person with cerebral palsy’ or ‘person with multiple sclerosis’ etc. As we have seen disabled people and their organisations have rejected the implications of the medical model of disability.

“Secondly, by linking disability to ‘impairment’ this phrase conveniently side-steps the consequences of institutional discrimination against disabled people - poverty, dependence and social isolation - and, by implication, the need for change.
they are disabled by society. As Darke (1998a) argues, 'there is no such group as people with disabilities; there are people with impairments and disabled people, but they are quite distinct things: linguistically, politically and theoretically' (224).

The linguistic challenge raised by proponents of the social model has been adopted within disability studies and remains the key principle in working for change on both an academic and an activist level. It has proven to be an effective method for challenging hegemonic discourse and it overcomes the problems of replacing "nasty" words with "nice" ones because it takes existing terminology and disrupts it so that it comes to signify new, more politically desirable concepts. It nevertheless faces difficulties in retaining the words "disability" and "disabled" because, outside the activist/academic discourse, most people still understand them to signify "physical impairment" and they still carry all the negative connotations that were associated with "cripple" and "crippled". But this is not proof that it is not a worthwhile project, as 'disability, like most dimensions of experience is polysemic - that is ambiguous and unstable in meaning - as well as a mixture of "truth" and "fiction" that depends on who says what, to whom, when and where' (Corker as quoted by Bricher 2000: 784).

‘Language, then, is not a system of signs with fixed meanings with which everyone agrees, but a site of variation, contention and potential conflict’ (Corker 1998: 226). Thus, injecting new meaning into an existing term requires perseverance. Hillyer (1993) suggests that this means that we have to exercise constant vigilance and to constantly define our terms. ‘Instead of taking for granted the meanings assigned by one or another political group, we can struggle with distinguishing our own definitions from theirs. The process is awkward; it slows down talk; it is uncomfortable. It slows down thought and increases its complexity’ (46). Changing language can be a painstaking process, but it is a vital one if we are to break down the prejudices which are concealed within existing language.

One of the difficulties of the social model's distinction between disability and impairment is that it ignores the possibility that impairment is likewise embedded in social, particularly medical, assumptions. In this respect, there are a growing number of theorists who argue that impairment is socially constructed and, as such, is as relevant a category for linguistic and discursive analysis as disability (Corker 1999a; Patterson and Hughes 1997,1999, 2000; Thomas 1999b; Wendell 1996). Thus, Thomas (1999b) argues that:

First, the term impairment, like any other linguistic category, is a social product, and as such possesses a cultural history… With this in mind, 'impairments' can be understood to be those variations in the structure, function and workings of bodies which, in Western

"Thirdly, it is an explicit denial of a political or 'disabled identity'. Since the emergence of the disability rights movement the words 'disabled' before 'people' or 'persons' has come to signify identification with this collective identity. Phrases such as 'people with disabilities' undermine that identity."
culture, are medically defined as significant abnormalities or pathology... Second, in my view it is too limiting to think of impairments as connected with a biological substratum, 'the human body', which is fixed... Rather, this 'biological substratum' is itself a social product, as well as a physically changing 'biological' entity (italics original) (8,9).

Once again though, this does not lead to a rejection of the arguments of the proponents of the social model. It simply points to the need to recognise the dynamic nature of language and the complex, ongoing requirements of linguistic change. Hence, the importance of a poststructural perspective, informed by semiotics, as it allows us to acknowledge that, because meaning is fluid and multiplicitous, it is in the slippage of meaning within and between words that the potential for resistance lies. Corker (1998), a disability theorist who has adopted a linguistic approach to challenge the inadequacies of the social model, concurs with this and states that '[p]oststructuralism deals specifically with language and discourse and, as such, is bound up with issues of meaning, representation and identity. Its main premise is that meaning can never be fixed because human discourse is constantly evolving and therefore continually engaged in creating new meanings' (224). Being liberated from essentialist views means that it is possible to change just about anything about ourselves and our situations because nothing is fixed or foundational. As Foucault (1991f) argues in relation to genealogical analysis, this kind of approach allows us to "separate out from the contingency that has made us what we are, the possibility of no longer being, doing, or thinking what we are, do, or think' (45-46).

**Drawing on Metaphor, Subversion and Slippage**

To be able to effectively devise new ways of speaking, new ways of being understood and identified, it is necessary to first understand how language operates. This, as I have suggested throughout, involves an appreciation of the fundamentals of Saussure's arguments as this helps us to understand that signs are arbitrary and that they have been developed within an overall system of language or *langue*. This gives us the key to understanding the social construction of identities and the potential for challenging them. But, I have also intimated that it is necessary to move beyond Saussure, because his interest in developing these principles was to demonstrate that there is a solid, stable structure of language, *la langue*, which predetermines and therefore delimits our choices of individual speech, *la parole*. In this way, the idea that speakers could become agents in creating new speech was antithetical to Saussure's need for fixity. Paradoxically, however, his principles pave the way for a deeper understanding of just how individual speakers can and do create new language and in this respect I draw attention to the work of Merleau Ponty.

It was Merleau Ponty (1964a) who was to draw from the foundations of Saussurean linguistics the possibility for what he refers to as 'truly expressive speech' (46). He concurs with Saussure that there exists 'a sedimented language that tends to consolidate, formalise, and regulate established meaning' but unlike Saussure he sees speech as a form 'which desires to break out
of these limiting circumstances’ (Koukal 2000: 602). Thus he argues that, although it is necessary that language be stable enough a system to guarantee relatively fixed meanings that can be understood over time, ‘[it] must nevertheless remain open to the initiatives of the subject’ (Merleau Ponty 1964b: 87). Pivotal to his recipe for "truly expressive speech" is the premise that new speech does not exist outside of the existing language structure, it lies within it, silently waiting to be brought to life.

A language sometimes remains a long time pregnant with transformations which are to come... since those which fall into disuse continue to lead a diminished life in the language and since the place of those which are to replace them is sometimes already marked out - even if only in the form of a gap, a need, or a tendency (Merleau-Ponty 1964a: 41).

I argue that it is within these "gaps" that the silenced voices of those who bear the mark of the Other can find the words and phrases to express the concepts which already frame their lives.3 Just because the words are yet to be found does not mean that the experiences, the feelings, and the subjugated knowledges which mark out their oppression are any less real. It is merely an indication that the dominant discourse, the sedimented langue, is retaining its hegemony.

Merleau Ponty (1962a) refers to these gaps as 'the threads of silence that speech is mixed together with' and argues that it is by uncovering these spaces between existing words that we can find ways of expressing the formerly inexpressible (46). He advocates the use of imagery, metaphor in particular, to overcome the limitations of existing language and refers to this kind of innovation as 'shaking the linguistic or narrative apparatus in order to tear a new sound from it' (ibid.). Koukal (2000) describes Merleau Ponty's proposed use of metaphor in the creation of linguistic innovation:

Metaphors invest one object with the emotional or imaginative qualities of another object in order to disrupt the sedimented meaning of instituted language so that the first object can be seen a new way... Metaphor is only one of the many tropes employed to achieve an evocative turn on the meaning of commonplace words. What all tropes have in common is an ability to "surprise" us, to "jolt" us, to "shake us up"... in a way that allows a new meaning to tumble from language (611,612).

In the remainder of this chapter I will suggest how metaphor can be and, in some cases has already been, used to redefine the disabled identity in ways which promise to loosen its ties to oppressive concepts. Added to metaphor, I argue, are other techniques for drawing from the "gaps" and

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3 I am extremely indebted to Rebecca Caines, my colleague and friend, who introduced me to the postmodern perspective and the possibility for resistance through gaps and silences. Our endless conversations in relation to the radical postmodern view which structures her work has allowed me a deeper understanding of the issues involved than I could ever have gained through struggling alone with such difficult texts.
"threads of silence" new ways of speaking about disability and those who are defined within its precincts. These are the processes of "subversion" and "slippage" which also utilise language's fluid and polysemic nature to bring forth alternative narratives, subaltern voices, subjugated knowledges.

Linguistically, one of the important things to recognise in relation to "gaps" is that '[t]he absence of a sign can be a sign' (Merleau-Ponty 1964a: 44). Within hegemonic discourse there are many concepts which are taken for granted, identities which remain unnamed and thus exist within "linguistic gaps," because they are considered to be part of the norm. As opposed to gender which represents two possible positions, male and female, disability, like race, exists in a dichotomy where the opposing category is not named. People do not consider "whiteness" or "ablebodiedness" or "heterosexuality" as part of their identities, while being "black", "disabled" or "homosexual" can figure largely for those identified as such. To address this, disability rights activists and theorists have created new metaphors which express what was previously taken for granted. The terms "nondisabled", "able-bodied" and "ablebodiedness" are used to describe the position or condition of those who have previously not been defined. Linton (1998) discusses how effective this kind of metaphor is.

The use of non-disabled is strategic: to centre disability... This action is similar to the strategy of marking and articulating "whiteness". The assumed position in scholarship has always been the male, white, non-disabled scholar; it is the default category. As recent scholarship has shown, these positions are not only presumptively hegemonic because they are the assumed universal stance, as well as the presumed neutral or objective stance, but also under theorised. The non-disabled stance, like the white stance, is veiled. "White cannot be said quite out loud, of it loses its crucial position as a precondition of vision and becomes the object of scrutiny" (Haraway 1989). Therefore, centring the disabled position and labelling its opposite non-disabled focuses attention on both the structure of knowledge and the structure of society (13-14).

In this way, from Merleau Ponty's "threads of silence" are drawn new ways of looking at the world, new ways of defining the structure of dissonance which makes disabled people feel like lesser human beings. The gaps in language, the silence of the Other, are already filled with the sense of something "not quite right" and it is by allowing for its articulation that the opportunity for change is given breath. As Hughs and Patterson (1997) say so forcefully, the use of the term "nondisabled" allows us to 'to reverse the stigma of "otherness" and throw it back at the oppressor' (333). In parallel with this, disability theorists have developed words like "disablism" and "ableism" to describe the social oppression to which disabled people are subject. "Ableism"
is probably the more accurate descriptor for the kind of oppression experienced by disabled people because it is built from the generic term in the same way that "sexism" and "racism" are, but both are in use and either will suffice at this stage to get the message across. Linton (1998) points out that we are more clear about what can be construed as sexist and racist language than what is "ableist", but that this is probably due to the fact that 'the nature of the oppression of disabled people is not yet as widely understood' (9).

I have attempted to draw upon metaphor, or what Ricoeur (1978) refers to as 'semantic innovation' (98), in developing the expression "disabled identity" to frame the concept of oppression which I believe is responsible for the low status and damaged self-esteem which characteristically accompanies serious, ongoing impairment and illness. I believe that the bringing together of the words "disabled" and "identity", as contentious as they both are individually, extends the recognition inherent in the social model that disability is socially invoked by forcing us to focus on internalised oppression as similarly constructed. The notion that identity can be "disabled" emphasises the fact that disablism entails more than the exclusion of disabled people from employment and public spaces, but that it also involves the denial of a desirable identity. My intention is to challenge the belief, constructed within medical discourse, that people who feel denigrated and worthless when they become incapacitated are merely displaying symptoms of poor adjustment to adverse personal circumstances. I wish to demonstrate, conversely, that this subjugated identity is socially imposed. This new linking of words to suggest a concept which has formerly been given little credence, if it has been given any at all, involves 'a semantic event that takes place at the point where several semantic fields intersect', which is Ricoeur's (1978) definition for metaphor (99). As such, reframing disability in terms of the "disabled identity" provides a building block in the gradual development of new meanings. It is bound to be superseded by more evolved metaphors as disability theory progresses, but I see it as a stepping stone toward a recognition of why disabled people have to suffer from the additional hardship of internalised oppression.

The making of metaphors is a difficult process, however, and is often fraught with the problems associated with the elementary semiotic approach where new terms are often rejected due to their euphemistic nature or lack of effect. An intermediary phase is required where we work within the language that already exists by subverting it, disturbing it, giving old words new meanings, so that oppression is fought within existing logics while new language can undergo its halting burgeoning evolution. When disability theorists and activists redefined the meaning of disability and disabled, they were effectively subverting the meanings that these words had inherited from medical discourse (Thomas 1999b: 13). A more strident example of subversion is present in the use of "crip" within the disability rights movement. Like the words "nigger" and "queer", crip has been symbolic of oppression and, for similar reasons, activists from across these areas of identity politics have been "taking the bigot's labels of "crip", "nigger" and "queer" and turning them around to become badges of strength and
solidarity' (Corbett 1997: 95). Thomson (1997) writes of Nancy Mairs and her decision to take on the appellation "cripple" because it forces people to 'acknowledge the particularity of her body' (25).

'People . . . wince at the word "cripple", Mairs contends. Even though she retains what has been a derogatory term, she insists on determining its significance herself: 'Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger' (ibid.).

Claiming ownership over a word which was previously used in derogatory ways and investing it with new, more positive meanings leads not only to a new show of strength to those outside the liberatory discourse, it protects the individuals so named from being hurt any longer by the negative connotations that may still be inherent in other people's use of the term. This kind of subversion can therefore function to heal identities at the same time as attempting to re-educate society and revitalise language.

To fully understand the process of subversion, it is necessary to recall Butler's (1990; 1992) argument that identities, such as gender and sexual identities, are created through performative repetition. However, Butler also believes that these identities can be subverted through reiterative practices which demonstrate that they are not real, but are only ever performances. Thus she sees the performance of "drag", which imitates gender, as a parody of a parody as there was nothing real or essential to copy. Similarly, she argues that taking on the title of "queer" reverses its oppressive identifications at the same time as it plays them out, owns them, disturbs them.

Within queer politics, indeed, within the very signification that is "queer," we read a re-signifying practice in which the desanctioning power of the name "queer" is reversed to sanction a contestation of the terms of sexual legitimacy. Paradoxically, but also with great promise, the subject who is "queered" into public discourse through homophobic interpellations of various kinds takes up or cites that very term as the discursive basis for an opposition. This kind of citation will emerge as theatrical to the extent that it mimes and renders hyperbolic the discursive convention that it also reverses (Butler 1993: 232).

The same applies to the subversion of "cripple" as it also provides a theatrical challenge to its former meanings. According to Uprety (1997), those who have been forced to exist on the margins of society are in a unique position to subvert language and culture because of their 'hybrid identities' formed on the edge, both inside and outside the dominant culture. ‘From their vantage point of "double vision," those with hybrid identities can perceive they have an
understanding of multiple cultures, and they can use that understanding to create new forms of thought, new ways of aesthetic and political expression' (Uprety 1997: 369).

A particular instance of this is the way in which deaf activists have rejected the term "deaf", a term which represents the idea of hearing loss or impairment, and replaced it with "Deaf" with a capital D, which describes those who - as users of sign language in preference to the spoken word - are part of a linguistic minority. This involves an extreme subversion of the original concept of deafness and has resulted in the creation of a whole new culture, "Deaf culture". Corker (1998) points out that "deaf" became associated not only with hearing loss or impairment but was 'broadened to refer to any person who, regardless of whether they could hear or not, ignored, refused to listen or to comply to something or someone, and likewise, dumb became equated with stupidity' (225). The use of Deaf therefore subverts the original derogatory form of the word and, like the subversions of "disabled" and "cripple", functions to foster what is now referred to as "disability pride" (Corker 1999a: 203; Gill 1997: 45-46; Gilson, Tusler and Gill 1997: 16).

To be able to 'shake the chain of language' (Merleau Ponty 1964: 46) by drawing from 'the threads of silence' or 'gaps' new ways of saying things, either by building new metaphors or subverting existing terminology, it is vital to grasp the semiotic concept of "slippage". Perhaps Saussure's greatest legacy was his recognition that words are arbitrary and hence bear no essential connection to the meanings they express. In other words, the signifier and the signified are not linked by any natural or inevitable relationship. The only way that words take on any meaning at all is through their difference from other terms and this results in 'a constant sliding of meaning in all interpretation' because, in language, nothing can be fixed (Hall 1997: 33). This concept of slippage comes from Derrida's (2000 [1972]) development of the idea of différance, the neologism with which he captures the two meanings of the French verb, différer - to differ and to defer (87). By drawing on the idea of différance, Derrida extends Saussure's premise that words can only be defined in contrast to what they are not by demonstrating that this definition through difference or dissimilarity leads to a constant state of deferral of meaning. 'The sign represents the present in its absence. It takes the place of the present. When we cannot grasp or show the thing, state the present, the being-present, when the present cannot be presented, we signify, we go through the detour of the sign. We take or give signs. The signal. The sign, in this sense, is deferred presence' (ibid.).

This concept of slippage or deferral is useful to our linguistic excursion in two ways. It can help to explain how the words we have used to describe physical impairment have come to take on derogatory meanings and it can provide the theoretical basis for challenging language through metaphor and subversion. Consider, for example, the term "handicap" and the reasons for its rejection from the lexicon of disability theory. Why was "disability" chosen to be subverted rather than "handicap"? I suggest that this was because the word "handicap" was too tainted from the
"traces" of its former usage. Stiker (1999) touches on this view in his exploration of the replacement of infirmité with handicap in France.

In a single jump we have passed from a game of chance, the luck of the draw, and thus from a kind of natural fatality to a possible regulation, a will to master circumstance. A slight displacement of vocabulary and we have two different worlds in opposition: the world of disability, of insurmountable incapacity, and the world of handicap, of affliction compensated for... This image of horse racing corresponds exactly to that of the handicapped person who has to catch up, rejoin the normal and normalized group, be one of them. The horse racing application of the word is the right one. Handicap as a designation of disadvantage, illness, amputation, loss is secondary in comparison to handicap signifying competition, rivalry, participation in a trial (italics added) (146).

What Stiker is actually referring to when he speaks of 'displacement' is the slippage that occurs when handicap is transformed from its horse racing connotations into a new metaphor for describing disability. In its deferral from one meaning to another it changes signification 'without erasing the trace of its other meanings' (Hall 1990: 228). This is true of all words. In their fluidity and plurality they remain slippery and hard to pin down. According to Hall (1997), they always say 'something in excess of what we intend to say' and retain a fragility in which 'other meanings overshadow the statement or the text, where other associations are awakened to life, giving what we say a different twist' (33).

This lack of fixity is also the key to language change. Indeed, slippage is a primary device for both locating and negotiating the gaps in language. It is because meanings do not remain stable that it is possible to bridge the gaps and the silences with significations which have the potential to transcend existing realms of expression. For example, in my use of the metaphor, "disabled identity", I am relying on the polysemic nature of both these words. Firstly, by using "disabled" I not only draw on the social model's perspective that to be disabled is to be oppressed by a society which undervalues and does not accommodate for people who have impairments, I also make use of its former traces which suggest denigration and vulnerability because the experience of internalised oppression includes these impositions. Secondly, it is the slippery nature of "identity" that is precisely the concept I want to suggest, for, while the idea of a fixed identity has been central to the construction of the Other, it is the postmodern notion of the fluid, pluralistic self which offers the possibility for choosing other ways of being. And through playing with language it has been my intention to demonstrate that the disabled identity has been constituted as such precisely because the dominant identity, the norm, can only achieve its shape through contrasting itself with what it is not. In other words, it is because of slippage that identity must define itself in relation to the Other.

For identity is a will-o-the-wisp, essentially nothing on its own. As Redman (2000) argues, "identities take their definition only from that which they are not, implying, for example, that the
identity of the supposedly 'civilised European' is constructed in relation to a range of 'different' others: the 'barbaric' African, the 'exotic' oriental and so on. Disturbingly, this forces us to think of these differential identities as inherently unstable. From the perspective of différance, the identity of the 'civilised' European is constantly haunted by the liminal presence of the 'black' and 'oriental' others against which it defines itself and into which it continually threatens to collapse' (Redman 2000: 12). But, as with the fluidity of language offering us a multitude of ways to redefine our position, the instability of identity provides the potential for challenging it at its roots. This is why disability is feared and frowned upon by Thomson's (1997) 'normates'. 'People who have an impairment can act as a reminder of our own frailty, our own susceptibility to morbidity and mortality' (Watson 1998: 147). And any attempt by disability activists to challenge, through language, the authenticity of the border between normality and alterity threatens to dissolve all the claims which shore up normality in the first place.

Contesting oppressive language can be fraught with difficulty, however. Not only are there problems inherent in the transferral of negative traces from one word to another, but the dominant ideology bears a deep resistance to change. Griffiths (1995) argues that the normative group will fight tooth and nail to retain its position and that this is why politically correct language has often been referred to so scathingly and turned into a joke. Foucault (1985) acknowledges this resistance to change in his use of the ancient Greek parrhesia to describe the kind of 'free speech' with which is necessary to defy the norm. Foucault considers parrhesiasts to be those who are in a position 'less powerful than the one with whom he or she speaks. The parrhesia comes from "below", as it were, and is directed towards "above"'. The act of parrhesia is critical in nature and incurs risk or danger on the individual who is attempting to speak new truths.

In his later work Foucault (1988)) developed the notion that it is possible to develop ways of formulating our own subjectivities through stripping away universal "truths" and replacing them with our own personal truths, truths built on our recognition of how we would like to define ourselves outside of hegemonic discourse (15). For Foucault, parrhesia provides the means with which to reach this goal and it is in keeping with this understanding of 'free speaking' that I adopt the concept of parrhesia to encapsulate the processes of metaphor, subversion and slippage described above. For, it is only by being critical of what they are asked to take for granted and by being willing to risk the condescension, disbelief and harsh judgments of those who collude with the system as it stands that disabled people can attempt to redefine their positions and their identities. It is not that parrhesia will unearth a real "truth" which has been concealed by power, it is that it allows for the formulation of alternative truths, the means for articulating the subjugated knowledges that have formerly been denied a voice.

The struggle to devise new ways of articulating identity through parrhesia will only be effective, however, if it manages 'to enter into mainstream society and to struggle with hegemonic
discourses which mark the domains of its social reproduction’ (Corker 2000: 447). As I have attempted to outline throughout this chapter, the formation of meaning through language operates simultaneously at the level of semiotics, semantics and discourse and it will only be through working for changes at each of these levels that linguistic innovation and, accordingly, the resignification of marginalised identities can be achieved. I believe that the most powerful way to sum up the fact that our subjugation and our chances to resist it are tied up in the discourses which define us comes from Foucault.

Discourses are not once and for all subservient to power or raised up against it, any more than silences are. We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart it (Foucault 1980d: 100).

It is thus within language and discourse that the potential to unshackle the disabled identity lies.
CHAPTER FOUR

The Paradox of Disability Culture:
The Need to Combine Versus the Imperative to Let Go

Politics that ignores our identities, that makes them "private," is useless; but nonnegotiable identities will enslave us whether they are imposed from within or without (Phelan, 1989: 170).

What has become evident to me as my project unfolds is that my research relies on the existence of, or possibilities for fostering, some kind of group identification between disabled people. Both in my attempt to delineate a sample of people whose stories are assumed to contain common themes and my belief that from these stories will emerge emancipatory insights which have the potential to inspire and liberate other people who have experienced similar kinds of internalised oppression, I rely on the notion of a group of people, disabled people, who, like women and non-white racial groups, can be shown to share a subjugated identity. However, the attempt to articulate a collective experience between similarly oppressed peoples rests on a paradox which cannot be easily solved. For, how can we claim unity without falling into the same exclusionary practices which have served to create our divisive identifications in the first place? And, conversely, how can we relinquish the practices of identification which are based on binary oppositions without losing the ability to claim identities at all?

The articulation or imagining of a disability culture which can be seen as 'a kinship based on identification of shared understandings of common life experiences' (Neath and Schriner 1998: 218) has powerful implications. It enables a sense of connectedness which can break down the feelings of isolation and alienation that stem from the belief that disability is a personal tragedy which necessarily excludes the disabled person from full social participation, it offers empathy and acceptance between group members, and it provides a space within which positive identities can be constructed. Gilson, Tusler and Gill (1997) name the benefits of group recognition for disabled people as follows.

Learning to feel self pride in being disabled, identifying and supporting role models, encouraging exposure to and interaction with other disabled children and disabled adults, developing coalitions for change, learning the skills of self advocacy, ...confronting our own prejudices about one another while we build our self-esteem ...[and encouraging disabled people] to determine and relate their own stories (11, 16).

Moreover, as Robert Murphy (1987) points out, the most important effect of identifying with disability culture is 'the transformations of consciousness’ it makes possible. This new way of
seeing oneself and one’s situation is, as Murphy claims, ‘one of the best available forms of rehabilitation’ (157-158).

Yet, if creating a sense of group affiliation between disabled people is such a positive and empowering practice, why then do so many of the people whom I would define as disabled, those who have impairments or illnesses which lead to their social exclusion, choose not to identify themselves as such? Moreover, if joining together in response to a sense of shared experience and common purpose is such an effective tool of resistance, then why does there exist so much tension around the concept of identity politics? Why do some theorists and activists argue that the declaration of a common identity is as disempowering as the exclusionary logics it attempts to replace? And, if as its critics claim, identity politics has remained trapped within a modernist paradigm which essentialises difference and retains the dichotomies which are responsible for exclusionary discourses and practices in the first place, what are the alternatives? This chapter will be dedicated to exploring these problems and reframing them, not as insurmountable obstacles, but as vital indicators which point the way towards an effective means by which disability culture can be reconstituted as a liberatory device.

**Denying the Disabled Identity**

The failure of most people with disabilities to identify with other people with disabilities is, I believe, the principal contradiction that limits the DRM’s [Disability Rights Movement’s] potential influence and power (Chariton 1998: 78).

It is easy to understand why a great many people who are ill or otherwise incapacitated would attempt to escape the label of disability. For, as it has already been demonstrated, to be thought of as disabled is to be seen, as Goffman (1963) reminds us, as ‘not quite human’ (15). There are those who can hide their disabling conditions by attempting to appear as “normal” as possible, disguising the overt manifestations of their impairments and doing everything they can to keep up with the pace and expectations of an able-bodied world. And, even for those whose disabilities cannot be concealed, it is still possible to avoid identifying with other disabled people by attempting to overcome their disabilities and maintaining their former identities and kinships as much as possible. Yet, there are also other reasons for not identifying as part of a culture of disabled people which have more to do with the lack of cultural roots and sense of unity that are evident in other groups which are founded on the shared experience of subjugation.

Unlike women and non-white racial groups who have relatively clear boundaries defining their cultural groups and close connections with other members, people who become disabled often have no ties or sense of relationship with other disabled people at all. Whereas women, for example, are usually surrounded by other females who can provide empathy, role models and a shared heritage in women’s stories, those who become disabled have usually grown up in
families which did not include disabled members and, because they have been socialised into the belief that disabled people are unacceptably different, they are more likely to experience a sense of alienation than affiliation when disability occurs. As Gilson, Tusler and Gill (1997) explain:

For many of us who acquire a disability after childhood, we have no friends with disabilities, before or after gaining our disability identity. Many of us growing up with disabilities have few peers with disability. We do not have playmates, friends, or confidants who share our unique identities and perspectives. Lacking positive, successful disabled role models we choose to appear, act, and behave as non-disabled as possible in order to survive (8).

This lack of cultural history and interaction can be seen to be similar to that experienced by lesbians and gay men because being socialised within an able-bodied, heterosexual environment can only lead to intense feelings of isolation and alienation when either of these unspoken prescriptions can no longer be performed (Scheer 1994: 252-253).

Added to this lack of cultural heritage, the likelihood of being able to see disability as a phenomenon which overarches a great many people's experience is reduced by the tendency within medicine, political programmes and charitable organisations to divide disabilities into distinct categories which are seen to be mutually exclusive (Bryan 2001: 326). After all, what could the experiences of blindness and chronic fatigue possibly have in common? This kind of thinking, however, stems from the tendency to focus on the impairment, the physical problem, rather than the disability, the social outcome, and leads disabled people to feeling trapped within a purely physical, personal situation. Swain and Cameron (1999) also argue that this separation is an integral part of normalising discourse.

The separation of disabled people into impairment-specific categories has also served to reinforce the impact of the individualising discourse, creating a situation in which people have identified themselves as more or less disabled. The less disabled an identity that someone has of herself, the more she has been able to aspire towards "normalcy" and the less bound she has felt herself to associate herself in her own mind with other disabled people (76).

This kind of division which leaves disabled people feeling isolated and disconnected from most other people with impairments results in 'a politically powerless and diffuse class of people who are unable to coalesce with other groups of disabled people' (Oliver and Zarb 1997: 196) and often leaves intact the tendency for disabled people to retain their discriminatory attitudes towards other people who have impairments.
Those who acquire disabilities have usually imbibed the prevailing attitudes about disability during their former able-bodied lives and these prejudices do not magically disappear when a person becomes disabled. Neither the internalised oppression that results from disability nor the impetus, via rehabilitation, to overcome it and regain a normal life challenge the negative views which surround the notion of disability. Karen, one of Thomas's (1999b) research participants declares that 'although I am extremely embarrassed to admit it now I was reluctant to define myself as disabled, carrying as I did all of the prejudices I had somehow adopted in my able-bodied days' (53). Another research participant expresses these kinds of prejudices even more vividly.

The thing about M. S. [multiple sclerosis] and being disabled is that it takes you away from your normal peers ... The normal peers are replaced or people try to get you to replace them with these grotesque others, with whom under normal circumstances you have nothing to do with and still have nothing in common with except disability (as quoted in Charmaz 1987: 299).

These kinds of prejudices are very difficult to shake and, as was discussed in Chapter Three, they are internalised by the disabled person in the creation of the disabled identity. Such negative attitudes serve to keep the disabled person isolated, not only from the rest of society, but from those who could provide comfort and inspiration by way of their shared knowledge in relation to the experience of disability.

Much of the prejudice which has led to the denial of any kind of culture of disability has been exacerbated by the fact that, up until fairly recent times, any notion of a collective identity has been devised by the able-bodied and foisted on disabled people in ways which have not been welcomed by them. This is due to the fact that disability is representative of a group defined by the practices of cultural imperialism and is 'identified by outsiders without those so identified having any specific consciousness of themselves as a group' (Young 1990: 38). This kind of external identification which results in people being thrust together in ways that are uninvited is evident in two of the essays written for Paul Hunt's book in 1966: The Experience of Disability. In one, Ford (1966), a man with muscular dystrophy, complained that he had often been forced to attend meetings which were comprised solely of other people with muscular dystrophy.

While it is undeniable that for many who might otherwise be housebound and completely cut-off, such meetings do provide opportunities and facilities for social contacts ... We do not want to be segregated into insulated groups of individuals who may have nothing in common except their physical condition (36).

In the other, Chalmers (1966), who was forced to attend group outings with other people with polio, similarly lamented that 'it seems odd that people are expected to enjoy being together merely because they are all incapacitated' (25). He goes on to state, in keeping with his clearly
held belief in the necessity to rehabilitate and normalise, ‘I am convinced that such dwelling on
one’s disease is wrong, and that the whole endeavour of the victim should be directed towards
getting back, if not into step, at least into the company again of his own calculated pace’ (ibid).

These kinds of attitudes are completely understandable in the context of the medical model of
disability which informs them. According to this view, disability is an individual problem which
must be solved by individual effort and the desire to return to as normal an existence as
possible. Not only was the idea of group identity thrust on these people from without, it was a
notion that was in complete contradiction to their understanding of the recovery process. The
medical view of disability does not foster a group consciousness based on the idea of shared
oppression. It was not until the last two decades that disabled people began to join together in
response to their common experience of subjugation and, subsequently, to seek a different form
of “recovery” and “rehabilitation”, one based on a social understanding of disability.

Nevertheless, although a group consciousness has been growing among disabled people, the
majority are still loathe to identify themselves as disabled if it can be at all avoided. As Hahn
(1985) argues, disabled people ‘are understandably reluctant to focus on that aspect of their
identity that is most negatively stigmatised by the rest of society and to mobilise politically
around it’ and they ‘experience difficulty in developing a sense of identity with an attribute of
themselves that they have been taught to “overcome” ’ (310). To deal with such negative
perceptions, both their own and others’, many disabled people choose to pass, a coping
mechanism defined by Hillyer (1993) as the ability ‘to present yourself or let yourself be taken
for a member of a more privileged group’ (136), a choice which Goffman (1963) believes to be
irresistible ‘because of the great rewards in being considered normal’ (95). Passing as an able-
bodied person or, when passing is impossible, ‘covering’ the disability as much as possible
(Goffman 1963: 125), exacts huge costs from the disabled person in the form of ‘emotive
dissonance’ (Hillyer 1993: 150) ‘anguish’ (Linton 1998), and in purely physical terms. It also
effectively forecloses any desire or ability to affiliate with other disabled people because the
category is seen to be unacceptable.

Even for those who eventually identify as disabled, the choice to pass may well form part of a
transitional phase in which the disabled person comes to terms with his or her spoiled identity.
As Tepper (1999) explains, hiding one’s disability and pretending to be “normal” is similar to
keeping in the closet one’s lesbian or gay identity. The distress and discordance this double life
creates for the person who is suppressing such a major part of themselves, however, often
leads to the decision to “come out”.

Coming out, then, for disabled people, is a process of redefinition of one’s personal
identity through rejecting the tyranny of the normate, positive recognition of impairment
and embracing disability as a valid social identity. Having come out, the disabled person
no longer regards disability as a reason for self-disgust, or as something to be denied or
hidden, but rather as an imposed oppressive social category to be challenged and broken down (Swain and Cameron 1999: 76).

It is important to note that the process of identifying as disabled does not involve passively accepting a negative identity. It requires challenging these negative notions at their very roots. As Gilson, Tusler and Gill (1997) argue, ‘[o]nce we begin to transfer from the world of the non-disabled to affiliation with the disability community, the meaning of disability and of having a disability shifts for us’ (8). I would argue that this shift in meaning stems from the reciprocal linkage which ties culture to language. As I suggested in Chapter Three, being part of a culture which is built from emancipatory ideals involves being able to develop new words, or to attach new meanings to old ones, in the attempt to forge a positive group identity.

This process of coming out and coming together as group of people bound by the shared experience of oppression can be extremely liberating. By bringing together a formerly disparate collection of people who were isolated and powerless, alienated and ashamed, it is possible to develop a group consciousness based on the recognition that what was once seen as an individual tragedy is in fact a social creation that can be challenged and changed. The sense of kinship which grows from the emergence of a disability culture allows for the breaking down of past prejudices and the creation of new stories which can be built from the subjugated knowledges which were formerly buried beneath the medical model’s assumption that to hide one’s disability and pretend to be as normal as possible is the best way to cope. This experience of finding a voice, rearticulating what it means to be disabled, and throwing off the shackles of individualising discourse allows for the healing of the disabled identity. The words of Joy Weeber (1999b), a woman who spent most of her life in a state of emotional discordance until she discovered a sense of kinship with other disabled people, express this process of healing with great beauty and clarity. I thus choose to conclude this section by quoting from her at length.

I have come to know the healing of belonging, of being understood without a word in a community of people who validate my feelings. I did not know how fragmented I was, and I needed other disabled people to teach me to love myself wholly! I had needed them to teach me how to embrace that part of myself that society so devalues. I needed them to show me the commonalities between our experiences of ableism and others’ experiences of racism. I needed them to give words to the feelings I had never had reflected back to myself in my nondisabled world…

I am proud to have found my way home to the disability community. I am now able to "hang out on the porch" and hear stories from the elders of how their visions of equal justice for all took shape, how legislation acknowledging our civil rights was passed. And although it is true that we continue to struggle to define our own lives and live it on our own terms, we have also begun to create a culture that brings us together and celebrates our unique ways of being in the world. I am moved when I hear poetry that
speaks my truth and read books that truly reflect my life experiences. I am healed when I see unflinchingly honest performances dealing with the reality and pain caused by ableism. I now know that I have indeed experienced the pain of ableism and I know why I felt the pain of racism when I had words for neither. I now also know the liberating power of embracing my disability and of celebrating who I am because of it. (22, 23).

**Overcoming the Paradox of Identity Politics**

As empowering as the creation of a sense of disability culture has been for people who were once trapped in the net of individualism which masked their oppression under the guise of personal troubles, it is based on a notion of identity politics which 'has become a double-edged sword' (Humphrey 1999: 174). "Identity politics" is the term used to describe movements and theories, such as those predicated on feminist and anti-racist sentiments, which are based on the recognition of shared oppression and among whose major goals 'are forging a [positive] image or conception of self and propagating this self to attentive publics' (Anspach 1979: 766).

In outlining the paradox which troubles the celebration of an identity hewn from oppression, Humphrey (1999) concedes that identity politics 'is an inescapable necessity for oppressed peoples, offering itself as a safe space in which people who share similar conditions of existence can heal from the wounds inflicted by the world, debate the societal origins of their affliction, and grow into survivors with the strength to fight back' (ibid). Yet he also warns that 'if it becomes the ultimate destiny for oppressed peoples, it will also metamorphose into an inescapable tomb' because it relies for its existence and its potency on the exclusionary logics which created it in the first place (ibid).

The problems inherent in claiming a collective identity to work for social change have been discussed by social theorists at length over the past decade, most notably perhaps by Judith Butler (1990) in her exposition of the problems inherent in declaring gender a unified and unitary identity from which to launch an emancipatory politics for women. She posed several probing questions which I believe serve to articulate the problems that all theories based on identity politics share.

Is the construction of the category of women as a coherent and stable subject an unwitting regulation and reification of gender relations? And is not such a reification precisely contrary to feminist aims? …If a stable notion of gender no longer proves to be the foundational premise of feminist politics, perhaps a new sort of feminist politics is now desirable to contest the very reification of gender and identity …[and] to formulate within this constituted frame a critique of the categories of identity that contemporary juridical structures engender, naturalise, and immobilise (5).

These concerns are equally relevant to the problematisation of disability culture as envisaged by disability theorists and activists, because, to rely on an identity based on the reification of an
oppressive category imposed by hegemonic discourse does not challenge the assumptions upon which it is based.

It is now commonly accepted within the field of disability studies that the possibilities inherent in the structure of disability culture to reinforce oppression must be properly understood and remedied. Davis (1998) warns against the tendency to base emancipatory action on 'the notion of wounded identities' (29). He quotes Brown's reading of Nietzsche to argue that the ontology of the coming into being of wounded identities is an 'effect of domination that reiterates impotence, a substitute for action, for power, for self-affirmation that reinsurance incapacity, powerlessness, and rejection' (ibid). In this way a collective identity based on shared oppression is based on 'remembering and reinvoking the pain caused by oppression' (ibid) and, as such, it 'installs its pain ...in the very foundation of its political claim, in its demand for recognition as identity ...by entrenching, restating, dramatizing, and inscribing its pain in politics' (Brown as quoted in Davis 1998: 29).

A great many disability theorists are working to clarify the issues which articulate the paradox which is born from relying on a sense of a stable, unified identity when this claim to stability and unity is in actuality the source of oppression for people who have been declared inferior (Corker 1998, 1999, 2000; Davis 1998; Linton 1998; Meekosha 2003; Scheer 1994; Thomas 1999a, 1999b). In drawing from their insights and attempting to weave them together into a coherent narrative, I argue that this paradox rests on the fact that identity politics bases its claims on essentialist assumptions which result in the maintenance of the modernist, dichotomous thinking which has been responsible for the creation of dividing practices in the first place.

This essentialist belief that identities have a natural origin manifests itself in two ways, both of which trouble the emancipatory potential of disability culture. The first and most commonly cited is biological essentialism which posits that identities stem from innate biological causes, such as sex-related physiology, genetically explicable racial differences, or physical damage which leads to incapacity. Alternatively, and equally problematic, is the form of essentialism which is defined by Laws (1995) as 'humanist essentialism' (116) which relies on the modernist belief, discussed in Chapter Three, that identities are stable, unified and continuous entities (Woodward 1997: 11). In the following two sections I seek to demonstrate that each of these brands of essentialism are responsible for keeping the possibilities for collective action and redefinition ensnared within the oppressive binaries that negate the value of difference and diversity, and I will conclude this chapter by arguing for the relinquishment of the desire for fixity and permanence within categories of identification.
Getting Underneath the Skin

Escaping from the essentialist assumptions which haunted early forms of emancipatory struggle has been one of the prime tasks of feminists, anti-racial activists, and disability theorists over the past two decades. For, by accepting that their identities had a biological basis, women, non-whites, and disabled people faced an early stalemate in their development of liberatory theories because they were restricted to the argument that their differences made them "naturally" or essentially better people than those who had defined them as inferior. Thus, women who claimed that their innate ability to nurture, be maternal and to form close relationships provided the tools for overcoming the oppressive and hierarchical nature of patriarchal rule, while understandably trying to develop positive identities based on their shared oppression, were missing the point that the differential nature of these qualities was in fact constructed as the roots of their subjugation. The recognition that their oppression had relied on the construction of a subjugated female identity led to the development of the distinction between sex, the biological category, and gender, the social construction, a position which appeared at first to effectively oust its essentialist assumptions.

I would argue that disability studies has traversed a parallel pathway to feminism and has undergone a similar theoretical evolution in its attempt to deal with the problems involved in claiming a collective identity. Indeed, disability studies and feminism are founded on very similar ideals, as Thomson (1996) outlines:

[Both] challenge existing social relations; both resist interpretations of certain bodily configurations and functioning as deviant; both question the ways that differences are invested with meaning; both examine the enforcement of universalising norms; both interrogate the politics of appearance; both explore the politics of naming; both forge positive identities (22).

And, I would argue, both have had to negotiate the problems which have stemmed from claiming a biological origin for their political categorisation. As has already been discussed in earlier chapters, disability studies has attempted to overcome the biological determinism inherent in medical discourse by developing the social model of disability which distinguishes between the physical reality of "impairment" and the social creation of "disability" and I believe it has achieved great theoretical strides by being able to argue from a more constructionist perspective. However, the problems of situating impairment outside social and historical debate mirrors the problems which Butler (1990) brought to light within feminism when she questioned the feasibility of dividing off gender from sex, a socially created identity from the body upon which it has been inscribed. What, she asks:

… circumscribes that site as "the female body"? Is "the body" or "the sexed body" the firm foundation on which gender and systems of compulsory sexuality operate? Or is
"the body" itself shaped by political forces with strategic interests in keeping that body bounded and constituted by the markers of sex? (129).

The dividing off of impairment from disability as social construction is a similarly troubled concept. It leaves impairment, and the pain and suffering which accompany it, as untouchable areas of experience, which, as I have argued throughout, disallows theoretical analysis from getting underneath our skins to the source of some of the most distressing facets of our oppression. As Meekosha (2003) argues, proponents of the social model risk the creation of a ‘new binary … - impairment/disability - as the theory attempts to remove an older powerful binary - normal/disabled’ (64).

Paterson & Hughes (1997) have argued that, by ignoring the social construction of the impaired body, the social model converges in a dangerous synchrony with the individualistic biomedical perspective it sets out to critique.

The social model - in spite of its critique of the medical model - actually concedes the body to medicine and understands impairment in terms of medical discourse. To recapture this lost corporeal space without returning to the reactionary view that physicality determines social status, the social model requires to mount a critique of its own dualistic heritage and establish, as an epistemological necessity, that the impaired body is part of the domain of history, culture and meaning, and not - as medicine would have it - an ahistorical or, pre-social, purely natural object (326).

In a nutshell, any claim to identity which rests on a division between the biological and the social will be weak in two ways. Firstly it will suffer the price of theoretical inconsistency by relying on an arbitrary distinction between a socially constructed element and one which defies this construction. For how can we argue for the social construction of the former, if we subscribe to the belief that the latter is mimetic, that is, that it reflects an inherent reality which has escaped the forces human interpretation? And, secondly, it leaves the area of experience surrendered as biological at the mercy of annexation and this serves a doubly subjugating purpose. For, if disabled people's pain and personal anguish are claimed to be irrelevant by both the medical model, which sees pain and distress as deficiencies in coping, and the social model, which promises to emancipate disabled people if they suppress any aspects of their conditions which may be considered to be individualising, they remain in a no-man's-land where these facets of their reality are given no credence by either the discourses that are believed to oppress them and that which promises to liberate them.

One Problem, One Name, One Very Effective Prison

The second brand of essentialism I wish to discuss may be even more troubling than its biological counterpart because it is so seldom recognised as problematic. Laws (1995)
describes this kind of essentialism provisionally as 'humanist' or 'structural', but does not attempt to define it and Woodward (1997) touches on the same kind of notion and argues that it 'involve[s] tracing our routes through history of the assertion of binding kinship relationships' and adds that, like biological essentialism, it rests on 'a claim to a unified notion of identity' (italics original) (11). I argue that this form of essentialism is philosophical in contrast to biological and that it may be more clearly defined in relation to the development of the liberal belief in a stable, unitary identity discussed in the previous chapter.

As I attempted to demonstrate, although we are now aware of how fragmented and contingent our identities actually are, we are still tightly bound to a notion of identity which supports our need for fixity and unity. These conflicting perceptions, and, thus, the paradox which emerges from them, result in a case of double vision when trying to articulate the state of the late modern subject. The simultaneous view of the subject as both stable and constantly shifting, unified and fragmented, fixed and fluid, singular and hybrid, creates a sense of what Caines (2002) refers to as 'vertigo' in the face of these incommensurable realities. This dizziness and lack of orientation is also transferred to the ways in which we perceive collective identity and, as is the common tendency when we feel threatened with a loss of balance, we reach blindly for anything solid and grip as tightly to it as possible. I believe that this desire to cling onto what seems safe and comprehensible is at the root of our current dilemma within the realm of identity politics, for, although there are a multitude of theorists who are arguing passionately for the recognition of difference and diversity within liberatory movements, they remain loathe to let go of their philosophical understanding of identity as being synonymous with unity and continuity.

The need for unity at both an individual and group level is understandable and cannot be easily resolved. For, how can we feel whole or build emancipatory movements based on shared experience without claiming some sense of unity? As Haber (1994) points out: 'The recognition of similarity with others is crucial in denying and recognising the harmful political implications of the public/private split. It is the recognition of the similarity of my pain or oppression in someone else that allows me to deny the idiosyncratic nature of my experience, and to deny my guilt at being different from the "norm"' (133). However, this need to recognise the many and varied connections that inevitably exist between individuals does not necessitate the existence of an immutable, transhistorical identity which is based on fixity and the exclusion of other qualities.

In attempting to build a concept of identity within feminist theory which escapes the restraints of modernist thinking, Griffiths (1995) argues that 'there exists no unity of the self, no unchanging core of a being' (185). It is the desire to build meta-narratives which claim to represent universal truths about the human subject which has been responsible for the creation of oppression. 'Infinitely preferable', Griffiths argues, 'is the variety, confusion, colour, hotchpotch, kaleidoscope, medley, motley, and harlequin of patchwork selves' (ibid). What we need then is a way of acknowledging and utilising our shared experiences by deconstructing rather than
celebrating them, challenging rather than clinging onto them, coalescing around them to gain insights into how to release ourselves from their grip rather than tightening it ever further by not believing that release is possible.

The need to recognise the diversity of problems, values, experiences, stories and identities that exist within the group of people defined as "disabled" has been acknowledged across the board within disability theory. However, although a great deal of lip service is being paid to the notion that identities are fluid, fragmented and multiple, this often only thinly veils the modernist assumptions which underpin even the most poststructural of accounts. Every time disability theorists use the terms "we", "us" and "them" without qualification (Gilson, Tusler and Gill 1997; Morris 1991; Peters and Chimedza 1995) or speak of 'a conception of the self' (Anspach 1979: 766) or 'a whole self' (Weeber 1999a: 110) that does not acknowledge the many selves we are or have the potential to become, we are relying on unitary logics which risk excluding certain people. Thomas (1999a) refers to these collapses into modernist assumptions as 'categorical approaches' which 'suffer from the paradox …that by identifying with and celebrating their "difference" disabled people might reinforce and sustain (rather than challenge) categories which have been socially produced within an oppressive disablist and patriarchal society' (115).

In assuming that the "shared experience" of disabled people truly is "shared" by all its members, disability theorists have often overlooked the other strands of identity which affect the experiences of disabled people. Indeed, I would argue that the unacknowledged "subject" of disability studies has been overwhelmingly white, male and middle to upper class (Couser 1997: 185). Couser argues that women have been ignored because they are already considered to be disabled by their gender and Deegan (1985) adds that they are, therefore, seen as having less to lose than men (56-57). It is also becoming clear that the female identity has been neglected within disability studies because men have dominated due to their privileged status in society (Barnes, Mercer and Shakespeare 1999; Lloyd 1995; Meekosha 1998). This neglect of the issues concerning disabled women has not been limited to disability theory. Feminism has also demonstrated a lack of interest in including disability in its analysis (Barnes, Mercer and Shakespeare 1999; De Pauw 1996; Drake 1999; Lloyd 1995; Meekosha 1998) and has even been shown to incorporate discriminatory attitudes towards disabled women because they epitomise the passivity and dependence that feminists are trying to dissociate themselves from (Drake 1999: 131; Fine and Asch 1988: 3-4; Lloyd 1995: 219). The issue of race as it interacts with disability has also been notably absent in disability studies, as has the consideration of disability within the racial identity literature (Alston et al. 1996).

Deegan (1985) argues that, because the effects of multiple oppression are not calculable via the simple addition of the minority statuses involved, an adequate consideration of their interaction can only be developed within what she refers to as 'the multiple minority group' (39). While I understand the argument here, I also believe that, ultimately, it is based on the very
kinds of unitary assumptions from which oppressive thinking originates as it assumes that identity does, indeed, reside somewhere in the core of these ever smaller minority groups. And, in so doing, it denies the opportunity for emancipatory politics to challenge and disperse all identifications based on lack of social privilege. To take the notion of the multiple minority group to its logical conclusion, consider the outcome of dividing off all of the groups within disability studies which are representative of multiple minorities. All that would remain in the original group would be white disabled males (or perhaps rich, white, disabled, heterosexual males who are successful and independent and are not disfigured). I suggest that, rather than this, we understand the disability rights movement and all other groups which coalesce around the recognition of shared oppression as inherently multiple and that we all always need to be conscious of our mixed heritage in privilege and subjugation. Only then will we be able to choose to live outside of these groupings. Otherwise, if I am fighting to retain one form of privilege while I am struggling to overcome another, how do I reconcile my belief that all forms of oppression are wrong?

This recognition that we must move beyond the concept of singular groupings which are believed to represent singular identities is, I believe, the first and most vital step towards developing an understanding of how oppression is enacted so that it can be undone. And the only way to follow through in practice is to stop demanding uniformity and to start inviting and attempting to make sense of the many voices which are capable of articulating the experience of subjugation. If we can learn to see both that there are many other subjugated identities experienced by those who also see themselves as members of disability culture and that other marginalised groups outside of disability culture have shared similar experiences in their trajectory of oppression, then we have the beginnings of an emancipatory theory which is capable of dissolving exclusionary boundaries and working towards the celebration of the differences which exist beyond oppressive binaries.

Slack (1999) argues that, to prioritise diversity, we must open our ears and our minds to the different stories, 'the personal and unique histories' that make up the identities of people who are also disabled (36). Haber (1994) also speaks in terms of stories or narratives and the fact that their multilplicitous nature ensures that 'the recognition of similarity does not foreclose on the recognition of genuine difference. So long as I recognise the many narratives I am I can also recognise that any story about another, or about myself, is necessarily incomplete' (127). By accepting that the unique nature of our stories is based on their complexity and multiplicity, we have the potential to build identities which are not bounded by exclusionary divisions. As Thomas (1999b) argues, it is necessary to acknowledge that claiming affiliation with disability culture should not rely on a unitary claim to a disabled identity, but should be based on the understanding that 'one set of strands in one's web of identity - or one chapter in one's ontological narrative - has been subjectively acted upon, re-woven, and retold in the light of counter-narratives' (120).
Beyond the Disabled Identity

I believe that, although biological and humanist essentialism are based on different kinds of originary logic, they are both implicated in the same modernist stalemate which comes from seeking liberation by simply reversing the dichotomies which define who is privileged and who is excluded in our society. By claiming an identity which has been created through the processes of hierarchical differentiation and exclusion, subjugated peoples reinforce their own oppression and restrict their hopes to the belief that they can demonstrate how positive it is to be identified as such. This kind of thinking misses the point entirely. What we must do is to challenge the very frameworks within which this way of perceiving the world as "good" or "bad", "right" or "wrong", "worthy" or "unworthy" have been constructed. The question should not be focused on whether we have positive characteristics based on our disability, womanhood or racial origins, but on how these distinctions function in the first place and what, if anything, lies outside of them.

Foucault's argument that those who believe that sexuality is a natural quality which can be liberated from repressive influences is relevant here (Foucault 1977d: 155; 1980h: 219-220). I suggest that the same form of entrapment in essentialist logics is in evidence within disability theory and the disability rights movement, because, by claiming that there exists a more positive disabled identity which has been repressed, and that its authenticity is now being unearthed via the theories and practices which frame disability culture, the disabled identity becomes iconised as a true and unitary way of being. This is the problem with a concept such as "disability pride." It is admittedly symbolic of the positive identity sought after by disabled people, but it only really serves to reinforce the oppression that it is attempting to challenge. For, when "disability" is understood within its social model context, it refers to a marginalised status which should foster a desire to escape from, rather than hold onto and celebrate, it. What we can celebrate, however, is the strength we have developed through learning to survive in a world which relies on such negative identifications, our ability to create beautiful things from the rubble of our marginalisation, and, ultimately, our capacity to devise new ways of seeing ourselves which are inclusive of our impairments, but which exist outside of "disability".

In keeping with this recognition of the importance of the repressive hypothesis, Simon (1995) states that 'Foucault was not interested in reversals that simply affirmed what had been repressed, be it sex, madness or delinquency, but in those that begin with such affirmations in order to dissolve the categorisations or subjections that construct sexual or other natures' (98).

In other words, it was not Foucault's aim to affirm our social construction via identity, but to work towards the creation of liberatory forms of subjectivity. I would argue that this ability to use the concept of collective identity in the service of overcoming it revolves around the recognition of the difference that exists between "being" and "becoming" as articulated by Hall (as cited by
Woodward 1997: 21). Woodward discusses Hall's concept of an 'imagined community' built on both a shared history of "being" and the freedom to "become" other than this (ibid).

Although he may use different words to describe it, Foucault's work is liberally infused with references to this need to move beyond an imposed sense of "being" into the realm of "becoming". Thus, when he suggests that 'maybe the target nowadays is not to discover what we are, but to refuse what we are' (Foucault 1982: 216) he is clearly articulating the difference between a sense of identity as "being" and one which involves "becoming", because he is suggesting that, by refusing what we are, we are capable of becoming something else. The evolution of effective liberatory theories and practices relies not, Foucault (1991a) argues, on the clinging to formerly inscribed identifications, but rather on the 'destruction of what we are... [and] the creation of something entirely different' (122). Many theorists have been concerned that the notion that even our most "private" domains are socially constructed serves to preclude any hope for agency. Yet, as Foucault (1988g) argues, these social constructions 'can be unmade, as long as we know how it was they were made' (37). This, as I have argued, is the purpose of the genealogical project. By seeking to uncover the buried knowledges of erudition, the histories of the present which disturb the self-evident nature of our most deeply held assumptions, we open the way for other choices, other "truths", other ways of seeing ourselves. I refer once again to Simon's (1995) observation that 'genealogy exposes the contingency of what appears natural, enabling one to loosen the ties to one's identity' (109). This does not entail a necessary rejection of behaviours that have traditionally been associated with oppression, such as, being "feminine" or "maternal", rather it reframes these positions as choices instead of immutable facts of nature.

The liberatory potential of post-structuralism is, however, queried by authors such as Thomas (1999a) who declares that 'for anti-essentialists there cannot be an identity politics' because 'identity politics is seen as re-inscribing the very boundaries it seeks to challenge' (116). With this I can only agree wholeheartedly. But, while Thomas uses this premise to destabilise the anti-essentialist assumptions of poststructural theory, I argue, conversely, that the call for the dissolution of identity politics as we know it is a sign of poststructuralism's success not its failure. For, although I concur that we need to coalesce around our points of common oppression to be able to overcome them, I do not believe that this necessitates that we lionise this identity and declare it a permanent feature of either society or our subjective realities.

Instead, I argue that we should move beyond the reification of oppressive identifications, and see our collective struggles as temporary and partial responses to instances of injustice based on negative identifications. These groupings should not be allowed to calcify into fixed categories from which we cannot escape. They should be viewed rather as "communities of resistance" which must be capable of changing their shape to adapt to the differing
circumstances within which subjugated identities are framed. Foucault (1977c) touches on this need for fluid rather than fixed forms of resistance when he argues that 'if power is dispersed in a multiplicity of networks, resistance can only be realised through a series of localised strategies' (italics mine) (126). Strategies which are localised and particular are capable of taking into account the specificity of each claim to a more positive identity or enhanced social status and can be based on coalitions which are 'provisional', and, as such, are constantly 'subject to recreation and renegotiation' (McNay 1992: 111). Wallace Balogh (1991) puts this beautifully when she describes this kind of coalition as 'creating a space, ...a holding environment' which paves the way for change:

The ongoing process of creating a holding environment for ourselves and each other, a social, intellectual space for political, intellectual sociability, for reflecting on our given "realities", strengthens and empowers us to address and challenge the oppressive and repressive nature of those realities and the representations of those realities (41).

This will only work, however, if as Caines (2000) argues, these partial and momentary collectivities are recognised as a function of 'a hybridised identity' (126). In arguing for an understanding of community which celebrates rather than fears its lack of fixity, she argues that, if our connections are recognised as fluid, partial and momentary, 'then the community networks built from groups of these connections can never be traced to a hierarchical or oppressing singular purpose, vision or voice' (ibid).

This idea of a community of resistance which forms in response to shared oppression is based on an understanding of identity which attempts to move beyond the constraints of essentialism. This has been a difficult vision to clarify because many theorists, like Connolly, who use poststructural theory and the genealogical method to explore alternative ways of viewing identity, remain tangled in the paradox which demands as its solution the retention of a stable notion of identity. Connolly (1991) expresses it thus:

Now, the paradoxical element in the relation of identity to difference is that we cannot dispense with personal and collective identities, but the multiple drives to stamp truth upon those identities function to convert differences into otherness and otherness into scapegoats created and maintained to secure the appearance of a true identity. To possess a true identity is to be false to difference, while to be true to difference is to sacrifice the promise of a true identity (Connolly 1991: 67).

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5 The term and the concept of “communities of resistance” was first used by hooks (1990b: 43). I originally believed that these “communities of resistance”, like the identities they coalesced around, would dissolve when they had been successful in their goals, but my supervisor, Trish Harris, pointed out in an email to me that ‘oppression doesn’t get beaten once and for all. It adapts, accommodates, takes on new forms etc. So I wonder if this doesn’t need a rethink suggesting that your ‘communities of resistance’ are not fixed but fluid; that they take new shape and form as the patterns of oppression respond and change’. 
Yes, it is true that we cannot hold on to our notion of true identities when we recognise that we are made up of multiple, fluid and changing points of subjectivity, and neither should we desire to. "True" identities are built on "truths" which are created, via expert knowledges, for the purposes of shaping our behaviour and they bind us to narrow, fixed choices of how to see ourselves and do not represent our complexity at all.

Thus, the problem with envisaging the disabled identity as representing something inherent in the natures of people with impairments that should be celebrated and maintained is that it negates the possibility for existing outside of it. One of the prime purposes of disability culture is to struggle against the fact that, as was discussed in the previous chapter, being "disabled" has been turned into a 'master status' (Becker 1963: 32-33) or a label of 'primary potency' (Singh 1999: 88). Does this not necessitate both that the recognition that people who are incapacitated are part of an extremely diverse group of people and that the attempt to reinscribe their identities in ways which are not framed by oppressive definitions, result in the dissipation of the disabled identity altogether? Davis (1998) discusses this possibility, but is obviously vexed by the outcome.

The list of identities will only grow larger tied to an ever-expanding idea of inclusiveness. After all, when all identities are finally included, there will be no identity. When studies focus on alterity, and when alterity must be included, then, in the full plenum of inclusion, alterity ceases to be other. Identity becomes so broad a category that it cannot contain identity (22).

I realise that Davis is referring to the methodological difficulty inherent in declaring the struggle for emancipation a universal objective, but I argue that the problems he outlines, that, if alterity is included it will no longer be other, and that, when identity is dissipated through a declaration of difference and a celebration of diversity then it will cease to exist, are in actuality the solutions to the paradox of identity politics.

It should be apparent by now that I am not aiming for the creation a more positive disabled identity. I aim to challenge it at its roots and argue for its dissolution. This form of resistance does involve the creation of positive identities, but they will be positive because they exist outside of subjugated identity formations not because they celebrate them. They will be the identities that are possible when we are no longer defined by dichotomous polarities, but can freely choose to become individuals who are more self-determined and who are capable of challenging the social imposition of identity. This includes people who have been defined as "normal", as existing on the right side, the desirable side of the dichotomy. By understanding their enslavement to the principles of the norm, they can be more free to choose the ways in which they would like to be identified. This kind of identity formation would be based on a continuum of accepted and acceptable difference where difference is celebrated, and not on a hierarchical dualism of self and Other where difference from the norm is punished.
This view of identity and the communities of resistance it implicates need not shatter our current applications of disability culture as a tool for social change. However, it will necessitate that these sites of collective struggle are utilised in different ways. My method of research represents one possible means for building a partial and temporary community of resistance which is capable of devising new ways of "becoming" from its exploration of the processes of "being". It functions by combining the historical project of genealogy with the telling and unpicking of narratives which represent, to various degrees, both phenomenological examples of the ways in which the dominant discourse is woven into people's identities and the counter-narratives which have been built in their scattered locations within the grid of power as subversions of these identities. Both levels of perception are evident in participant narratives and I believe that, via the theoretical insights outlined so far, each can function to educate us on how to move beyond oppressive identifications. For, by learning how our most personal experiences have been fashioned as part of a historical project which governs our lives, we can begin to choose differently from the array of subjectivities that define each of us.

To balance an understanding of the elements of shared oppression with the positive differences which are possible outside of binary classifications will require a constant rearticulation of the ways in which we describe difference and diversity. The metaphors which we create to challenge our subjective locations will have to be malleable and capable of change as our connections to our common bond in oppression become weakened by our success. "Crip", for example, will only achieve its parodic purpose during the early phases of transition towards more enabling forms of identity, and the term, "able-bodied" need only exist to trouble the boundaries between those who are accepted and those who are not while those boundaries are still in evidence. Similarly, the descriptor, the "disabled identity", becomes redundant when people who have impairments and ongoing illnesses are not defined by them, but are characterized by the diversity of their qualities which include, but do not prioritise, the physical state of their bodies.

In conclusion, I should make clear that the process of liberation that has been suggested within this chapter relies on the mapping out of what Foucault (1991f) refers to as ‘a critical ontology of ourselves’ (43). To challenge our identities and to loosen our ties to them requires that we attempt to work ‘at the limits of ourselves’, at the boundaries which define and divide us (ibid).

I mean that this work done at the limits of ourselves must, on the one hand, open up a realm of historical inquiry and, on the other, put itself to the test of reality, of contemporary reality, both to grasp the points where change is possible and desirable, and to determine the precise form this change should take (ibid).

In Chapter One, I suggested that the point at which a person moves from a state of ablebodiedness to the social location defined by the disabled identity is marked by a hybrid and
heightened state of consciousness of the margins which separate the privileged from the excluded. And I now reiterate that it is this liminality which makes it such a salient site from which to launch a critical ontology of ourselves.
PART THREE

Speaking the Unspeakable:

Tales of Loss and Healing
Since I became acquainted with you, this question of identity has lodged in my thoughts like a grove of trees, sometimes offering shelter, sometimes mysterious and even a wee bit scary, the home of strange and powerful spirits.

Chris Baker, email correspondence 30/5/02

As I tuck myself beneath my computer table to begin the writing of this, the most important section of my dissertation, I am momentarily awestruck by the emotional complexity of the task ahead and I am faced with a quandary. For, how can I possibly share what a deeply moving and intensely transformative experience my communion with other disabled people and their stories has been, while maintaining the professional tone that such an academic analysis demands? A typical essay designed to describe a piece of grounded theory research will begin with an introduction which discusses background issues and the reasons why the research is believed to have academic value, and will then describe the nature of the sample and methods of data collection and analysis. Following this will be a breakdown of the results where the main categories and themes are outlined and, finally, there will be a discussion of the theory or theories which have emerged from the data.

All of these are vital ingredients in an informed and informative account and I intend to neglect none of them. However, I propose that, due to the differing nature of my particular methodology, the way I structure this account will need to deviate from the conventional format. My introduction has already been given and comprises the first four chapters of my thesis. Within Parts One and Two I have attempted to describe my methodological rationale and to set the scene for how it is that the disabled identity has come into being. Added to this, a significant portion of my data analysis and the conclusions drawn from it will be dealt with in the next
section, Part Four of my thesis, when I apply a governmentality analysis to the main themes which emerge from this, the qualitative component. Therefore, what remains to be addressed here, apart from a description of the sample, the sampling technique and the data coding process, are the stories themselves and the insights they generate. What I most desire to create here is an emancipatory space in which the stories, built from the dialogues and autobiographies and my own personal experience, can retain their integrity while being viewed from the different angles that a categorical analysis necessitates.

Therefore, I will attempt in Chapters Five through Eight to provide the space for the telling of the stories which have emerged in the context of the core categories. It is within these four chapters that I most wish to deviate from a conventional approach. Firstly, there will be no attempt to formally embed these stories in referenced sociological texts. I believe that the sociological foundations, as I argued above, exist in the arguments and analyses presented in the chapters which come before and after this section. Additionally, as outlined in Chapter One, it is my intention to develop these chapters through a very subjective lens. It will be subjective in that the following interpretation of the data is completely my own and, although it rests on a strong theoretical background, as outlined in Parts One and Two, it is also heavily influenced by my own experiences of disability.

It will also be subjective because I intend to interweave my own voice with the voices of my participants. This has already occurred within the dialogues I had with them because I tried to be very open about my own feelings in relation to disability and I see the dialogues as being representative of conversations between equals. However, in addition to this, my voice will also be present in the weaving together of the emergent themes. In other words, I will attempt to be open about my own feelings and experiences where I feel they have relevance. A further difference between this and a conventional grounded theory account is that I wish to ensure that the excerpts I draw from the dialogues and the written material are clearly linked to their contexts, and for this reason these excerpts will be quite lengthy at times, so that they are not fractured unnecessarily to support my interpretations. Lastly, I often refrain from mentioning a person's impairment when I quote something that they have said because frequently this information is irrelevant and its addition would only serve to support the idea that disability should form the primary mode of identification for those who have impairments. Appendix One, however, provides a basic description of the participants, including their age, geographical location, nature of impairment(s) and/or illness(es) and time since the onset of their impairment(s)/ illness(es).

At this point I would like to make an attempt to share the feelings of awe, inspiration and gratitude that have grown inside of me over the preceding months in response to my conversations with my participants, feelings which seem to me to epitomise the transformational potential inherent in this kind of approach. I am honoured to have met such a diverse group of
truly exceptional people and to have been offered an intimate look into their lives, thoughts and emotions. This willingness to share on a very intense and, at times, painful level in the hope that it may help other people in similar situations, established the atmosphere for our discussions and, I believe, created a space in which an extremely valuable consciousness raising process was encouraged to occur. In support of this belief many of my participants have indicated that the opportunity to discuss or write about their identity issues has been helpful, in some cases simply to let off steam and in others because it has made them think about things in completely new ways. In my own case, the impact has been enormous. My view of my life, myself, my disability and my future has been completely revolutionised and it is my hope that the emancipatory insights which link my qualitative research experience with my new self-perceptions will infuse every layer of my thesis from this point onward.

**Methodological Considerations**

Before proceeding to the stories themselves, it is necessary to engage in a brief discussion of the methodological consequences of attempting to merge genealogy with grounded theory. Fundamental to the principles of grounded theory is the proviso that the researcher must approach the study at hand with no preconceived ideas about the outcome of the research. As McCann & Clark (2003a) reiterate in their encapsulation of grounded theory, it initially involves an inductive process which ‘requires the researcher to use a ground-up (from practice to theory) approach, to enter the field with no preconceived hypotheses from the literature or elsewhere, and to be open-minded and flexible, so that the theory emerges from the data’ (9). Its inductive nature makes it ideally suited to emancipatory research because, in the case of dialogical data generation, it does not impose any particular hypothesis on the narratives which are to be gathered and, as such, allows for the participants to tell their own stories in their own ways and for emergent theories to develop directly from the rich bank of data which is built from these stories (Hill & Thomas 2000; Kushner & Morrow 2003). Indeed, Knox et al. (2000) argue for the adoption of grounded theory specifically in the case of disability research because it contributes to the development of an emancipatory research model: ‘a model that fosters maximum control over and input into research endeavours by people with disabilities’ (50).

However, I diverge from a strict adherence to the “tabula rasa” approach by declaring such a strong theoretical standpoint from the outset. As I make clear in the preceding chapters, I bring to the grounded theory component of my research a strong social constructionist viewpoint, a practice which is becoming increasingly common within the field of grounded theory (see, for example, Marsiglio et al. 2001; Hill & Thomas 2000). I believe that this concern for social structure and context addresses one of the major weaknesses of traditional grounded theory studies, that is, that they have the potential to ‘concentrate on the immediate contextual factors that impinge on a phenomenon and ignore the broader structural influences on the phenomenon’ (McCann & Clark 2003b: 23). Denzin (1989) builds his methodology, “interpretive interactionism”, from the same foundation in
symbolic interactionism as grounded theory, but he adds a constructionist layer in the attempt to incorporate an awareness and analysis of social structures and power relations.

This concern for power and for how power twists and shapes human experience gives interpretive research a critical thrust that is often absent in conventional evaluation studies. Interpretive studies should provide a thorough going critique of the social structures and social processes that have been investigated. This will involve a critique of the general cultural formations that stand behind the phenomenon in question. It will also involve a critique of the intellectual-scientific thought that creates knowledge about the problem (Denzin 1989: 33-34).

In adopting a genealogical approach founded on disability theory and poststructuralism, I follow Denzin's emphasis on merging the biographical with the historical in the development of middle-range sociological theory, but choose to retain the coding procedures of grounded theory because I believe they serve to prevent my preconceptions from affecting an open-minded and fresh perspective in relation to the data (see Charmaz 1990). As McCann & Clark (2003a) argue, this process of data fragmentation and reassembly, particularly the initial intensive line-by-line coding process, ‘forces the researcher to concentrate on the data and avoid undue influence by preconceived beliefs about the field of enquiry’ (14).

Additionally, although disability theory and poststructuralism inform the fundamental premise upon which the entire project is based, that is, that identity and disability are social constructs, this premise is not a hypothesis nor is it part of a hypothesis that I seek to test. It is, rather, a conclusion drawn from prior research, one which has become what is referred to within the field of grounded theory as a ‘theoretical sensitising concept’ (Marsiglio et al. 2001). These sensitising concepts, and what Hill & Thomas (2000) refer to as ‘theoretical orientations’, are vital components of our research because they stem from or form biases which need to be explicitly stated ‘so that findings can be interpreted in light of this bias, thus increasing the credibility of the study’ (197). Glaser & Strauss (1967) were aware of the importance of these concepts and orientations when they first developed grounded theory and wrote:

As we have frequently remarked, researchers often stifle potential insights by virtue of too strict adherence to existing theory, particularly "grand" theory. Nevertheless, no sociologist can possibly erase from his mind all the theory he knows before he begins his research. Indeed the trick is to line up what one takes as theoretically possible or probable with what one is finding in the field. Such existing sources of insight are to be cultivated, but not at the expense of insights generated by the qualitative research, which are still closer to the data. A culmination of both is desirable (253).

It is important to note that, although Glaser (1992) remains sceptical of pre-existing theoretical orientations and maintains that the literature review should not be engaged in prior to data collection, Strauss & Corbin (1990, 1998) diverge from this view by developing an approach which draws on social constructionist ontology and poststructuralism and encourages a review
of existing research and an acknowledgement of social context and theoretical positioning as long as these do not stifle the development of insight during data collection and analysis.

My basic research question can be stated as follows: what affect does the onset and ongoing existence of an impairment have on people’s self-perceptions and how other people view and react to them? This question is intended to get to the heart of the identity shift which occurs in response to disability without imposing any preconceived ideas on what these effects might be. I had certainly experienced a dramatic change to my own identity when I became disabled, but, prior to the dialogues, I had not really been able to clearly articulate or categorise the nature of the rather diffuse feelings of inadequacy, shame and loss which had resulted. It was only through the dialogues that the categories began to emerge and through the process of analysis that they ultimately took shape. Thus, although I approached the qualitative component of my research with a strong belief that my feelings were a form of internalised oppression rather than a personal response to a tragic event, and an associated commitment to analyse the results in light of the constructionist perspectives which inform the social model and genealogy, I undertook the dialogues with an open mind and was to meet with startling new insights again and again.

**Sampling and Analysis**

Some months before beginning the dialogues, I emailed fifty seven disability related associations and support groups around Australia. Within these introductory emails I summarised my research objectives, explained the nature of the stories I was seeking and asked whether my call for participants could be included in a newsletter or posted on a list-server where relevant. In addition to this I sought participants by word of mouth in my local area. I was aware of the difficulties in attracting participants to this kind of research because, firstly, the kind of people who comprise my research population, by the very nature of their conditions, are often so challenged in their attempts to negotiate the processes of daily living that they lack the time, energy, health or freedom from pain to be able to engage in anything else. Secondly, I was asking people to discuss issues which can be of an extremely personal and painful nature. Therefore, I knew that I would need to spend a great deal of time and effort in the attempt to make these contacts and that my "hit rate" would be relatively low. For this reason, and because I believe that it is a technique which aids in the theoretical sampling component of grounded theory, I expected to gain many of my participants via the process of snowball sampling where participants would introduce me to new participants.

What I did not envisage was that this process of snowballing would expand the geographical boundaries of my research population to the degree that it ultimately did. Some months after my first attempts to attract participants, a woman in New Zealand, Lesley Tyzack, heard about what I was doing and emailed me. She is a disability rights activist and psychology student who has
been focusing on the issues of disability and identity in her own studies. She felt that my research complemented her own aims to such a degree that she was keen to help in any way possible. Through a snowballing process initiated by her I was eventually approached by nine other New Zealanders, many of them activists, who were willing to share their stories with me. The geographical boundaries of my research continued to expand due to the unpredictable pathways formed by electronic forms of communication and I was approached by people in the United States and the United Kingdom.

It quickly became apparent that telephone conversations would provide the best way to conduct all of the participant dialogues, most obviously because of the distance factor, but, eventually they proved to be preferable to face-to-face interviews even when the latter were feasible. As Kidder & Judd (1986) point out, telephone conversations provide the same benefits as the personal interview, but are cheaper and easier to organise. Moreover, they are particularly advantageous in cases where participants experience pain, illness and/or mobility problems. As such, telephone contact allows participants to converse from the comfort of home, at times even from bed, and it is easier to alter appointed times or to cut things short if the effects of the disability or illness make it necessary to do so (Clarke & James 2003).

The 34 participants consisted of 18 women (53%) and 16 men (47%). Three participants live in the USA, three in the UK, ten in New Zealand and eighteen in Australia. It is important to point out here that, although the proportion of participants in the USA and the UK were relatively small in comparison to the Australasian contingent, when the length and number of dialogues with these participants are taken into account, they contributed 35% of the overall data derived from the 34 participants.

The group ranged in age from 21 to 68, with those over 50 years of age possessing long-term impairments which were not age-related. The mean age was 45. The time since onset of injury ranged from 2 years to 58 years with a mean time of onset since injury of 18 years. The range of impairments reported was extremely diverse (see Appendix One). Although it had been my intention, for the reasons stated in Parts One and Two, to focus only on people with acquired disabilities, two of my participants and some of the autobiographical authors were born with their impairments. This provided the possibility for valuable comparisons to be made and similarities and contrasts noted. At the time of the dialogues, 7 persons - 3 females and 4 males - were in paid employment, ten were students and the remainder were unemployed. Ultimately, however, I decided that, like Low (1996), it was not of great importance to "stratify the sample by sex, age, class or race as my intent was not compare the experiences of different categories of [people] with disabilities, rather it was to explore the experience of [people] with disabilities in general" (236). Appendix Two lists a range of significant differences between sample sectors,

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Note that three people were both students and in paid employment.
The dialogues were commenced after informed consent was given (see Appendix Three for consent form) and ranged in time between one and three hours. With the exception of Lesley Tyzack, Lee Trustrum, and Chris Baker, who specifically requested that their real names be used, pseudonyms were assigned to each of the participants to protect their privacy. The way the conversations began varied. Often participants had already provided details of their impairments during prior email correspondence and the dialogue was initiated with the question: “How has [the illness or disabling condition] affected the ways in which you see yourself and how others treat you?” If I didn't already have a clear idea of the nature of the impairment/s in question I would begin by asking for more details. However, frequently the conversation had already begun in the email correspondence preceding the first telephone contact, so the starting point varied according to what had already been discussed. As part of the dialogue I shared details of my own disability related experiences and it appeared to me that this aided a great deal in the building of rapport.

Of the 34 participants, 22 spoke to me directly, 12 provided written responses, and 2 provided both spoken and written responses. In the case of the dialogues, the number of exchanges engaged in with each person varied according to whether additional conversations were seen to be mutually desirable and, if so, at the completion of each conversation we would renegotiate whether and when to speak again. In all, 52 dialogues were entered into (see Table One for a breakdown of the numbers of dialogues engaged in with each participant). The 12 participants who gave written responses provided them in the form of already existing essays, diary excerpts, email dialogues with me, or single pieces of writing which were written specifically in response to my basic research question. They ranged between one page and 35 pages in length.

<table>
<thead>
<tr>
<th>Number of Participants</th>
<th>Number of Dialogues</th>
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<tr>
<td>11</td>
<td>1</td>
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<td>8</td>
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<td>1</td>
<td>8</td>
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<td>Total 24</td>
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Table One: Number of Dialogues Per Participant
In addition to the contributions of these participants, I also analysed 27 autobiographies and 31 anthology contributions (see Appendix Four). Prior to starting the process of reading the autobiographies and anthologies I was uncertain as to whether they would function as comparable pieces of data as they had been produced in isolation from my research process. However, I kept in mind Glaser and Strauss’ (1967) advice.

When someone stands in the library stacks, he is, metaphorically, surrounded by voices begging to be heard. Every book, every magazine article, represents at least one person who is equivalent to the anthropologist informant or the sociologists interviewee. In those publications, people converse, announce positions, argue with a range of eloquence, and describe events or scenes in ways entirely comparable to what is seen and heard during field work. The researcher needs only to discover the voices in the library to release them for his analytic use (163).

In the case of the autobiographical material, in almost every case, these books, essays and poems could easily have been written in response to my basic research question: “How has [the illness or disabling condition] affected the ways in which you see yourself and how others treat you?” Therefore, those which were identity-oriented were treated as equivalent data slices and were analysed accordingly. Ultimately, the combination of the above processes resulted in the collection and analysis of 122 separate pieces of data based on the testimonies of 92 different people.

Fundamental to the development of grounded theory is the understanding that data collection and data analysis must not be viewed as discrete entities. From the earliest stages of data collection it is important to begin the coding process so that the emerging themes guide the ensuing collection of data. This is referred to as theoretical sampling and is used to ensure that the data guides the direction of the research rather than being used, as is the case in traditional studies, to prove or disprove existing theories and hypotheses (Glaser and Strauss 1967: 115). In this particular case, the technique of theoretical sampling did not so much affect the ongoing choice of participants, but rather indicated possible directions for the dialogues to take. Interestingly, however, I found that more specific questioning on sensitive issues frequently led to evasive responses and decided that the richest data resulted from free-form conversations rather than more focused dialogues.

Consistent with grounded theory methodology, data analysis occurred on three levels. First of all the transcripts, solicited documents, autobiographies and anthology contributions were subjected to an intensive line-by-line coding and memo-making process. I cannot overstate my astonishment at the effectiveness of this intense scrutiny. When transcribing a dialogue or extracting relevant excerpts from a book I found myself forming an overall picture of what was said or written in accordance with my preconceived ideas of what constitutes identity loss in
relation to disability. However, once I combed the data in a detailed way I became aware of how much "thicker" and richer this data was than I had initially assumed. The data seemed to take on much more of a life of its own and, although I would certainly still have affected its interpretation by my own attitudes and understandings, it unravelled and reformed in ways that were previously unimaginable to me. The next level of analysis involved the process of axial coding where comparisons were drawn between emerging themes, and the final step involved the abstraction of these themes into the conceptual groupings which constitute the core categories (see Charmaz 1994a).

Three core categories emerged from my analysis of participants' accounts, each of which interwove to define the major identity issues affecting disabled people. These were independence, work and appearance/sexuality. The following chapters will therefore be devoted to them. Before beginning this journey, however, it is necessary to highlight and discuss a crucial theme which emerged from the data, one which performed as the greatest confounding factor affecting data collection at the same time as representing the most potent symbol of how internalised oppression is played out in daily life. This, as it was defined by one of my participants, who is conducting her own research into disability and identity, is the practice of 'self-silencing'.
CHAPTER FIVE

Reaching Beneath the Compact of Silence

Of course we smile.
What else is one to do?
Despair will not penetrate
Defiance will not disintegrate this glass wall that surrounds us
And hostility will only puzzle you.
This smile covers a multitude of things -
The frustration of short-circuited human contact,
The deep-seated pain on loss of a whispered word,
The hidden but utter rebellion against the gods.
Would crying help?
Of course we smile.
It is our defence against The rest of you.

Norma James

After twelve years of inhabiting the problematic space defined by the disabled identity I should have known better. Yet, although I was well aware of the painful nature of the issues I was asking people to share with me, I was still naïve enough to assume that disabled people could and would have drawn clear and conscious boundaries between what they commonly shared with others and what they had learned should remain unspoken, and that they could move between these territories at will. In my own case I have learned to conceal from others and, at times, even myself, many of my feelings about my disability and how it has impacted on my life. After acquiring a disabled status it becomes apparent that there are certain socially acceptable ways of behaving and presenting oneself and that life moves more smoothly if one adheres to these expectations. Yet, beneath the social façade there live emotions submerged and losses unspoken and it has been my belief, one which is fundamental to my research aims, that a large part of the emancipatory process requires the creation of a space in which the unspeakable can finally be spoken.

This is more easily said that done, however, and during the early stages of the dialogical process I found myself caught in a conundrum. I had anticipated that our conversations would be dealing with two relatively distinct although interconnected phases, those defined by the loss of identity and the process of reconstruction. I expected that people would feel more
comfortable about sharing their experience of reconstruction as it is a much more positive and emotionally safe topic, but it was equally important to for me to be able to touch on the experiences of loss because of my belief that, if society did not hold such negative views about disability, the losses would not be as great. I wanted to give people the chance to be open about the kinds of things they had been encouraged to submerge, to validate their feelings and experiences in an empathetic environment, and to explore the ways in which these feelings and their silencing have been framed within the dominant discourse. However, the early dialogues and autobiographies seemed to focus almost exclusively on the narratives surrounding reconstruction, particularly when this was accompanied by a sense of triumph, and little time was devoted to expressions of loss.

My conundrum, therefore, lay in the question of whether my assumptions had been wrong. It was possible that people did not experience the deep sense of loss that I had anticipated and, even if they did, that they preferred not to talk about it. Either way, two of my foundational premises were seriously shaken, as I had strongly believed that all disabled people suffered, at least initially, from identity loss and that talking about it would be a welcome and emancipatory process. In relation to the former assumption, it quickly became apparent that everyone in the sample acknowledged their sense of loss. They just did not want to dwell on it when directly questioned. Consider the following dialogue. I am talking to Stan about a mutual friend who introduced us. Stan is very sympathetic towards her and feels she's been through a dreadful time.

Me: Has there been any similarity …. did [you also] go through a dark time? Early on?

Stan: I did, but I wasn't anywhere near as disabled as [her].

Me: Nor was I, but it's still difficult, isn't it, to come to terms with the losses, you know?

Stan: Well, the losses... I've been very, very lucky... I mean, all these overseas trips. My initial trip, my firm gave me six months leave on full pay.

Stan's reaction exemplifies the response that most people gave when they were asked a direct question about their losses. They agreed that they had experienced losses, but they would then quickly bounce off to safer ground, usually into what I refer to as a “triumph narrative”. My quandary became, if people were resistant to dwelling on the emotionally difficult times, then what right did I have to push them in this regard? In keeping with grounded theory principles informing my research and my natural inclination to respect people's boundaries, I believed it would be inappropriate to encourage them to talk about things that they obviously felt were better left alone. My understanding of the processes involved in this kind of avoidance was aided in a very significant yet unexpected way in another dialogue with Stan. It had been my practice to let my participants know that I am disabled as it was important to me that we viewed
the dialogues as a sharing of views between people who have experienced similar problems. Hence I was surprised to learn that I had not made this clear to Stan. He reacted with great sympathy.

Stan: Oh dear, I'm sorry to hear that. I sort of half-way guessed, but I asked you and you never told me [this must have been by email, but I don't recall]. So I'm sorry to hear that.

Me: Well, I'm like you and it's been for a long time and I've really come to terms with it. I mean, I'm trying to... I'm still trying to recover because I can't see any good reason why I can't get my back to start working again. I swim a lot and do lots of exercises, but it has definitely held me back. …

It was not until I transcribed the dialogue that I realised what I had done. When offered sympathy and an opportunity to discuss the difficulties I had faced, my immediate reaction was to shy away into a triumph narrative. I remember feeling quite taken aback by Stan’s sympathy and that my reaction was based on a desire not to be viewed as an object of pity. Dai Thomson (1986), in her anthology contribution about anger, points to how a false dichotomy has come to define the possible representations of disabled people.

Instead of acknowledging the basic humanity of our often-powerful emotions, able-bodied persons tend to view us either as helpless things to be pitied or as Super Crips, gallantly fighting to overcome insurmountable odds. Such attitudes display a bizarre two-tiered mindset: it is horrible beyond imagination to be disabled, but disabled people with guts can, if they only try hard enough, make themselves almost "normal". The absurdity of such all-or-nothing images is obvious. So, too, is the damage these images do to disabled people by robbing us of our sense of reality (78).

This dichotomy leaves no room for the expression of the infinite array of feelings surrounding the experience of disability and I believe that this is why most people tend to quickly shy away from the suggestion that their lives are defined by loss. And, in keeping with the recognition that there exists a continuum of realities between the extremes of total devastation and complete triumph, it is important to note that stories of triumph form a very important part of the disabled identity. They are just not the whole story. As was discussed in depth in Chapter Three, although it is important for people to see themselves as unified beings describable by a coherent narrative, our self perceptions are actually formed from a series of often contradictory fragments and we are constantly shifting our views according to our contexts. As Sarup (1996) argues about identities:

They are never finished products. Identities are stitched together out of discontinuous forms and practices. The representation of identity is an ongoing process, undertaken on many levels, in different practices and sites of experience. Identity is articulated in multiple modalities…(40) … When we talk about our identity and our life story, we
include some things and exclude others, we stress some things and subordinates others. This process of exclusion, stress and subordination is carried out in the interests of constituting a story of a particular kind (16)

Accordingly, I am telling the truth when I say, as in my dialogue with Stan, "I've really come to terms with it", but there are other stories which are not being told and there are powerful social forces in place which affect my choice of plot.

For, while I have in many ways "come to terms" with my disabilities, where coming to terms means that I feel good about my life despite and sometimes even because of what has eventuated from my pain and physical limitations, "coming to terms" often refers to socially sanctioned coping mechanisms which involve an intricate process of concealment. Recently, for example, I have had a new impairment thrust upon me and I am faced with new losses and the disquieting vestiges of old ghosts. I had come so far and now I have lost most of my hard won independence again. I have many different feelings inside in relation to these fresh losses and I am developing a variety of ways of interacting with others in relation to my current state. At one extreme I am very cheerful and intent on focusing outwardly on the lives of others. At the other I am twisted in knots of deep distress as I struggle to negotiate the process of "coming to terms" with my new physical and emotional reality. Both states are valid parts of my experience and my identity, and often the cheerful one is representative of a healthy attitude. But sometimes that happy face is merely masking feelings of absolute devastation and I fear what will happen when the mask inevitably cracks.

In relation to my quandary as to whether it was appropriate to initiate discussions which touched on the feelings of loss, which seemed vital to my research, but were evaded by my participants, I decided to stop referring to the losses and a surprising outcome became apparent. Ultimately, people were much more open about these issues when we came upon them in general conversation. Consequently, the dialogues proved to be rich resources for shedding new light on the experience of disability and, interestingly, one of the main themes that emerged was the process of concealment, the reasons behind it, and the decision that some people made, over time, to eventually break the silence. The remainder of this chapter will attempt to share these revelations.

Hiding the Pain

Many people talked about the need to hide the way they were really feeling and to show the world a positive face. They all spoke or wrote about a similar process of submersion, but they differed in the beliefs they attached to it. There were some who believed that it was necessary to accept their losses with stoicism and good humour and to get on with life. In these cases, there was a strong assertion that there would be no point in dwelling on the bad things.
Consider the following dialogues which occurred when I was still asking direct questions about my participants' feelings of loss.

[Robert makes light of everything, including the chemotherapy that he's just started having again.]7

Robert: Like I say, I'm a toxic waste dump going somewhere to happen [he laughs]

Me: That's how you'd feel, wouldn't you? That's one way of putting it. You've got a very colourful way of looking at things.

Robert: Yeah, well, you know, I don't...as I say to people, well, I could sit down and say [he makes his voice sound mournful and full of pathos], why is this happening to me? Why me? You know and ball my eyes out for hours a day and what good's it doing me?

Robert has had to deal with a range of serious illnesses and disabilities throughout his life, the most recent one being life-threatening, and he faces them with a fatalistic and jovial attitude. Janet expresses similar sentiments when she talks about the chronic pain she experiences in relation to a range of disabilities.

Janet: A lot of things just don't ever change and won't either. Some of it will improve, but, for example, I don't think the pain will ever go away... ever.

Me: So, how do you deal with that?

Janet: Well, sometimes I get fed up with it. But, on the whole, I don't let it bother me.

Me: Mmm [in agreement].

Janet: What's the point? To leave your life full of resentment and anger. What's the point in doing that?

The kinds of attitudes expressed here are often looked upon as being philosophical. What's the use in worrying about things you can't change? And it's very true. An important part of learning to deal with disability involves recognising that there is much in life that we cannot control and to find meaning outside of previous patterns of identification. Yet, as will be revealed in the section which covers the costs of concealing one's emotions, there is often a very fine line between making a good adjustment and burying vital parts of one's identity and reality. In earlier autobiographical writings it was common to see the expression of an exclusively stoic attitude, as in the following.

7 I use square brackets to enclose the remarks I have added during the transcription process, immediately after the dialogue occurred.
There was no doubt that the loss I had sustained was serious and final. It was equally clear that the situation had therefore to be accepted, and that "crying over spilt milk" would not help (Walter Thornton 1968: 11-12).

Blindness should not be regarded as an affliction: at worst, it is a nuisance which, with careful training, can to a great extent be overcome. For this attitude I am indebted to the intelligent and practical training given me by my parents, who by their own indomitable will taught us to “Keep your powder dry and your flag flying”. It was not always quite so easy as that; the powder sometimes became damp, the flag bedraggled; but their courage never wavered, and we tried to follow their example (Harold C. Dickinson 1983: 3).

Most of the participants, however, acknowledged that they were hiding their emotions and that their negative feelings would not simply go away. Hugh Gallagher (1998) writes about the impossibility of keeping things buried forever.

Flat denial of hard reality can serve a useful purpose - it buys time for coming to terms with trauma. Modern medical rehabilitation theory holds that, while temporary denial is normal, continued denial is unhealthy. Over time, according to theory, the psychic wound will heal: we will accept our condition and learn to like self and body as it is. We will learn, "It's OK," to be disabled.

It has not worked that way for me. I wanted it to, but it has not. For many years, should someone ask me how I felt about being crippled, I would answer, "It's OK with me! Never think much about it anymore." And indeed this was what I thought I believed. But this was just another form of denial at work. It was not OK, it has never been OK. In fact, I keened over my disability all the time, every day, all day; I just pretended to myself that I did not (Hugh Gallagher 1998: 5).

The following two quotes also acknowledge the wall that can separate people's interior worlds from what they believe they can share with others.

I have learned to be bright, loud, bubbly, friendly, funny, self-deprecating and to avoid ever communicating how I feel (Jacky, written story: 2).

During my travels I mourned, passing through stages of grief: denial, anger, depression, and acceptance. I felt as if a part of me were dying. It seemed as if I were watching helplessly as I disappeared and a sickly, dependent stranger for whom I had no respect was taking my place, stealing my hopes and dreams. But in the beginning I would not admit my anguish and sense of loss, not to myself or to others. I sank the worst of my grief deep in a lake within me, hiding the lake and the stone weight it hid (Melissa Anne Goldstein 2000: 96).
It would be wrong to suggest that it isn't possible that some people actually do deal effectively with their distress in the early stages of becoming disabled and go on to have meaningful lives without needing to reflect back on their losses. What does appear to be the case, however, is that many people find it hard to bury their pain and that they suffer in various ways from feeling pressured to do so. Yet, because I remained open to the idea that ridding oneself of negative emotions could aid in the process of healing, I tended to express this stance if appropriate to the particular conversation. On occasion this led to unexpected reversals as in the following dialogues.

Me: I guess that... if you're like me, I mean, having to, over the years, come to terms with disability and learning to deal with setbacks and disappointing things, physically and in other ways, you get in practice, don't you? Like it really gets you well honed in the skills of dealing with disappointment and pain?

Susan: I'd say that it skills you in hiding disappointment and pain.

Me: Ahh.

Susan: Not not feeling it. Certainly not.

Me: It certainly does do that.

Susan: It hurts just as much, but you learn not to show it.

Me: That's a big part of it, isn't it?

Susan: It's a sign of weakness. It's a sign of weakness when you already appear as a weak person, so you just can't go there, can you?

Me: Yeah, so a lot of it is the development of this apparent strength.

Susan: A lot of people say to me, gosh, you are strong. And I'm not at all. I'm very vulnerable. I'm upset very easily. But, I'm just good at hiding.

Me: Mmmm.

Susan: I must be a good actress or something.

When I posed the original question about how we learn to cope with difficulties and disappointments, that was exactly how I was feeling. I, like many of my participants, swing between seeing the submersion of pain as an effective coping mechanism and experiencing it as a process which discounts one's reality and leads to a sense of alienation and isolation. The following dialogue with another participant, Karen, greatly surprised me when it occurred. I had
already spoken extensively to Karen and this interchange occurred during our second very long and detailed conversation. She had come across as completely open about her feelings and her positive attitude seemed to accurately reflect her inner state. So, when I made the following statement, I did so in a genuine manner.

Me: I mean, you've got a bubbly personality and you can quickly show people how you are … and I'm sure that's been really helpful for you in that way.

Karen: It has, but also it can sometimes be… it can also be a pain, because... sometimes when I feel really yuck, I still have to be this bubbly person and I talk myself into being this person.

Me: I know. Yes.

Karen: And you can't break that pattern because it's been with you for so many years that this is you, but really it's not you.

Me: No.

Karen: It's just what you want people to see … I think the thing that got me started when I was growing up was that people used to say, poor wee thing because they just saw the wheelchair and I thought, what are you talking about, I'm not poor and so, of course, I just … started trying really hard to say to people, no, don't feel sorry for me, because I hated people feeling sorry for me. I really, really, really hated it, so I started being, I guess, being a different person.

Me: And it does [superficially] make you feel better about yourself, but, like you say, it creates that wall between you and other people when it comes to how you are really feeling.

Karen: Mmm, yeah and also, when you do finally end up with a relationship you do find it hard to show him how you are feeling. When you are feeling different you just always say sometimes that you are that person.

Me: Because you're so practiced at doing it. You do it automatically.

Karen: I'm professional at it [laughing].

This was the beginning of a lengthy conversation about the reasons behind, and the costs incurred by, hiding our real feelings. This conversation came to exemplify a process that was shared, entirely or in part, by many of those who had been dealing with disability for a long time: first one learns to bury one's feelings, even sometimes from oneself, then it becomes apparent that this is having a detrimental affect, often there is a crisis point, and then a resolution is
reached where one attempts to strike a balance between concealment and disclosure. Karen and many of the others spoke and wrote at length about the reasons they felt obliged to conceal their feelings, the costs this imposed and the final decision to speak out. These are the topics that will frame the remainder of this chapter.

**Why We Pretend it's Okay When it Isn't**

The multitude of different reasons that were given by disabled people to explain why they felt the need to build protective facades can all be seen as symbolic of a rational reaction to certain social expectations. In Chapter Three it was argued that the disabled identity is the outcome of internalised oppression, a marginalised sense of self which is mediated by a society which privileges certain norms, norms which are shored up by being contrasted with disability. Thus, in the attempt to avoid the stigma associated with belonging to a socially devalued group, it is natural for people to develop patterns of behaviour which, if they cannot disguise the disability altogether, will at least attract the most positive forms of identification on offer to disabled people. This awareness of the role that is expected to be performed by disabled people is made apparent in the following recipes devised by disabled people.

So I'm now a crip. That's my occupation, being a crip. And from the point of deciding on that definition, things become easy. I'm now formally and officially doing what I've been doing anyway. Being the best crip I can be. Being as cheerful as I can about my circumstances. Submerging my irritations and frustrations. Accepting as gracefully as I can that I need help a lot of the time. Being suitably grateful for that help. And above all, never being grumpy (Chris Baker 2001: 9).

As with all other social roles, a person can succeed or fail at sickness. A key rule for being a successful sick person is: Don't complain! The person who smiles and jokes while in obvious physical misery is honored by all. Doctors and nurses are especially appreciative of this kind of patient, for he usually follows orders and seldom files malpractice suits. Hospital visitors also value cheeriness, and the sick person soon finds that he is expected to amuse them, and thus relieve their guilt at being well. These are front-area, or on-stage, performances - to use sociologist Erving Goffman's celebrated theatrical metaphor for social interaction. The backstage behavior may be totally different, however, and the public hero may become a whiner at home. The bad patient is either tyrannical or a crybaby, or both at once. But above all, the bad patient is one who does not follow orders. There are, then, social skills in sickness (Robert F. Murphy 1990: 20).

He had worked very hard over the years to become a certain sort of person with a handicap. This person was the cheerful but not saccharine, confident but not cocky, direct, but not bitter, sort of person. He had become the person who accepts his handicap comfortably and, thus, makes others comfortable in its presence. He had accomplished this person by consciously projecting a secure self reliance. When
with him, people sensed they need not fear that he would burden them with his responsibilities. His mental state and physical condition were not contagious. He had learned early on that, no matter how kind, well-meaning, or determined another might be, he could or would not bear to assume a part of the real burden of being crippled. People flee from a sick room, leave their corpses on the battlefield, and prefer not to see their crippled neighbors. He often thought how much happier they would be if we were kept like lunatics in lunatic asylums or lepers in leprosariums. The price he paid to live in the world of the fit was to keep his burdens and his bitterness to himself. He tried - whether with friends, employees, or strangers - to be cheerful, healthy, interested, and never dependent or vulnerable. This makeup he assumed, like the movie star, but time was eating away at it. His life had become no easier (Hugh Gallagher 1998: 157).

When Hugh Gallagher decided to include the above entry in his autobiography, he pointed out that he had written the essay before he had his breakdown, before he had accepted that it was okay, indeed necessary, to be more open about the ways he really felt. He wrote it in the third person (as did Robert Murphy in the quote above) to distance himself from the pain it described. In introducing the piece, he wrote:

Today, reading it more than 20 years after it was written, I find myself shuddering and sad. I shudder because my life really was like that; I am sad that I lived so many years in such a state. I do think that this is a remarkable piece of writing, but it is not pretty. It is brutal and cold and angry. It depicts, all too accurately, what my life was like.

In attempting to fulfill these roles, disabled people hope to dissociate themselves from morally untenable positions, one of which is based on the belief that, if you talk about your pain, limitations or losses, then you are seen to be a whinger, or as Robert Murphy expresses it above, a "crybaby". In relation to this belief, Max Dashu (1986) writes in her anthology contribution which discusses the difficulties she had in being open about her epilepsy, "Some seemed to believe that to talk about your reality is to complain." This recognition is acknowledged in the title of another anthology, Mustn't Grumble, and a participant, Susan, also refers to this attitude in the following.

Susan: And the other thing people say is, you don't complain, do you? And I say, well, there wouldn't be a lot of point, would there? I mean, people get bored if you complain and they don't want to talk to you if you are going to whinge. And people say, you're really good, you don't complain.

What becomes apparent in the above observation is that, not only are we expected not to whinge, we are rewarded when we remain silent. Being recognised as a strong person who is
dealing well with a difficult situation is a powerful form of compensation for other identity losses. There is also another dimension to the isolation that results from becoming estranged. Sometimes our perception is not that we are choosing to remain silent. Rather, we are being silenced. Our realities are being actively avoided and our experiences and feelings are, thus, invalidated. Melissa Anne Goldstein (2000) discusses this in the following excerpt.

In some instances, I found that people avoided asking me "How are you?" by saying "You look so wonderful. You must be feeling better." Generally, they meant well. Implied in these words was the wish for me to feel better. But this greeting invalidated my suffering on the days when I was not feeling better. Sometimes this greeting was a way to forestall me from saying anything about my illness. Mostly, I just said thank you, but this left me feeling empty (98).

Many of the others already quoted for their references to self-silencing acknowledge that they do this in reaction to other people's expectations. When Susan noted that 'people get bored if you complain and they don't want to talk to you if you are going to whinge. And people say, you're really good, you don't complain,' she is acknowledging that the silencing process is reinforced not only through people's disapproval if you are open, but also by their approval, their positive reinforcement, if you do submerge the less pleasant features of your reality.

Closely associated with the preference for stoicism is the desire to be seen as strong. Disabled people do not want to be defined in relation to their physical "weaknesses" and often feel compelled to demonstrate strength. As Susan was quoted as saying earlier in relation to hiding her real feelings, 'It's a sign of weakness. It's a sign of weakness when you already appear as a weak person, so you can't just go there, can you?' Melissa Anne Goldstein (2000) also stresses the importance of remaining silent in the attempt to appear strong.

The way I coped with disclosure altered over the years. In the beginning, when I was still coming to terms with the lupus, I mostly kept silent, at times going to great lengths to keep my illness hidden. I did not like to acknowledge its existence. I feared the reactions of the person I told. I did not wish to drive people away, but neither did I want their pity. I wanted people to see me as I wished to see myself - strong, independent, and whole (101).

Melissa also makes it clear that being seen as strong is a tactic for avoiding the lurking threat of pity. As discussed in the introduction to this chapter, an aversion to pity is a prime motivator for keeping people either silent or focused on their triumph narratives. From my own perspective, the problem with feeling pitied is that it seems to negate all the other aspects of one's identity. Recently I visited a dental practice where the people understand my special needs such that the process of negotiating the dental chair is as safe as it can possibly be for my neck and my back. In my daily life when I am walking around it is not apparent that I am disabled, but seeing me try
to get on and off a dentist's chair brings my pain and limitations into high relief. At the end of my last visit, the dentist spoke with great sympathy about how awful my life must be and I can remember feeling that, although I appreciated the sentiments behind his comments, they also made me feel minimised, for I am so much more than my pain and awkwardness and I have built a life for myself that is far from ‘awful’.

The desire to avoid pity can lead to a very tenuous balancing act when a disabled person is trying to be open about his or her feelings and the person responding to this is attempting to understand and acknowledge them. I am not sure as yet how this minefield can be successfully negotiated, but I believe that it is connected with raising the status of disabled people in general. In this way pity can be replaced with a response which more closely approximates empathy, for we all experience hardship and exemplify different ways of being. Currently, however, pity often represents the unpalatable side of a dichotomy devised to define disability as a tragedy that needs to be overcome by, as one participant, Adrienne, put it, ‘meeting or exceeding the expectation of the norm… Instead of just getting rid of it.’

Adrienne’s observation that we should challenge the norm and ultimately ‘get rid of it’ points to a recognition which I believe should form the central rationale for any attempt to resist oppression and will thus be discussed at length throughout the following chapters. But, for most of us in our daily lives, the only immediate solution appears to lie in the attempt to approximate the norm as closely as possible. Hugh Gallagher (1998) calls this the ‘battle for normalcy’ and argues that it is the basic premise underlying rehabilitation philosophy (89). This ‘battle for normalcy’, in combination with the desire not to be pitied or in any way singled out, is expressed in the following example.

Me: But, you don’t necessarily want special treatment.

Glen: No, no, people don’t like that. They think you’re trying to gather sympathy. You know, you just want to be……I don’t like using this……normal…and treated like they’d treat anyone.

Melissa Anne Goldstein (2000) also expresses this desire succinctly when she argues:

Do we not see ourselves, at least partially, through others' eyes? When others perceived me as normal, it was easier for me to do the same and carry on in the everyday world defined by health. It helped me to fight against becoming trapped in the world of illness.

Ultimately, however, a fundamental reason for remaining silent, the fear which can be seen to underlie many of the other reasons, is that which is connected to the threat of rejection and abandonment. Many of the quotes already cited in this section acknowledge and incorporate this fear, as when Susan says ‘people get bored if you complain and they don't want to talk to you if you are going to whinge’ and when Hugh Gallagher (1998) notes that: ‘People flee from a
sick room, leave their corpses on the battlefield, and prefer not to see their crippled neighbors’ (157). When Melissa Anne Goldstein (2000) writes that the ‘dilemma’ of ‘disclosure’ involves ‘great risks’, the first of the risks she refers to is related to the fear of being ‘shunned or abandoned’ (99). Similarly, when Joni Earickson (1976) found herself in hospital after she had sustained a spinal cord injury, she wrote that ‘I was afraid people would stop coming to see me if I got bitter and complained, so I worked at cheerfulness’ (28).

Possibly the most compelling description of these feelings of rejection came from Karen who was earlier quoted extensively in relation to her admissions about hiding her emotions after having appeared to be completely open with them. Karen is now 38 years old and, unlike most of my research population, was born with her disability. She needs to use a wheelchair, but, other than that, was not treated, and did not see herself, as different from her brothers and sisters. It wasn't until her late adolescence that she was forced to face the harsh reality that she was going to be viewed as Other and that certain choices may be denied her. This was when she began being conscious of the need to project a special kind of image.

Karen: Yeah, and it's our way of coping because, you know, when you realise that you're different, being rejected is the biggest part. I don't like that feeling. I mean, no one would like the feeling of being rejected, but having a disability, that rejection seems to be ... it's all of you. They are not just rejecting something you might have said or done. It's because they're rejecting you... it always comes back to you being different because you have a disability.

What Karen touches on here is the terrible experience of being seen only as disabled and then being rejected on that basis. It is, as Karen laments, the ultimate form of rejection because you are not being spurned because of some personal failing, it is simply because your differences are seen as unacceptable. It feels like the whole of you is being rejected. As Karen says, ‘it's all of you.’ This is why Karen strived to become the kind of person that others could not help but love despite her physical difference. However, as she points out, this has meant that she has had to conceal huge parts of who she really is and how she really feels and, as I will be arguing in the following section, for some people this can create a sense of loneliness and isolation all of its own.

The Price of Silence

I have suggested that the reasons why it is common for disabled people to submerge a large proportion of their emotional lives is that their silence is linked to certain rewards which are sought in the attempt to gain social acceptance and to avoid stigma, disapproval and pity. Yet, it has also become evident that these perceived or sought after “rewards” do not come without a price. Some people point to the feelings of isolation that stem from keeping large parts of themselves hidden. Others talk about the depression and, in some cases, complete emotional
breakdown that can result. And, connected with both of these problems are the feelings of invalidation and the inhibition of true intimacy with a loved one that can result from the attempt to project only part of one's feelings and experiences.

When I focus on the experience of isolation, I question whether this isn't perhaps the most devastating disability-related experience of all. It certainly was in my own case. Recall that in the introduction to my thesis I wrote:

My life was shattered and by far the worst part of the experience for me was that no-one understood. I was completely, utterly alone and from behind the sheet of glass that separated me from the rest of the world I could not make myself heard. I had become, to all intents and purposes, invisible, without a voice and it is this kind of isolation that I want to break down by inviting disabled people to raise their voices through my research (3).

This loss of voice is simply terrifying. Initially, I had no concept of trying to stay silent. I was desperate to be heard. Part of what I wished to get across was that I was still the same person, with the same memories and similar aspirations. But the reaction I received from others was so discordant to the way I experienced reality that I ended up feeling like an alien who no longer shared a common language with those I loved. Silence came upon me slowly and with a stealth that masked its subtle implications. These days I am lucky that I have one or two people with whom I can usually share how I really feel. But, when things are particularly tough, like now, the chasm of alienation and estrangement shifts dangerously close to the feet I try desperately to keep wedded to solid ground, and still, far too often, I find myself swallowing what I would really like to say and choking on the fear that accompanies the possibility of ending up completely, utterly alone. For the true irony lies in the fact that, if I am too honest, I may end up scaring everyone away. Yet, if I conceal my inner being too well, the loneliness which results from being a stranger to one's most intimate friends can, in some ways, feel more distressing than actual, physical solitude.

Like me, Hugh Gallagher (1998) traces his deepest feelings of isolation back to the early days of being disabled, but, unlike me, he understood the need for silence right from the outset. He expresses similar feelings of horror at the thought of ever having to live through such isolation again. He was twenty years old when polio struck.

I lived for at least two weeks at the outer limits of pain. I was, however, well trained to hide my emotions. As a child, I had not been encouraged to express my feelings or, indeed, allowed to admit to having them. And so in the hospital I knew what was expected of me. With but few exceptions, I lived up to these expectations. I was of good cheer; I was a good sport; I complained as little as possible. I was helpful and cooperative, encouraging and inquisitive, aware and thoughtful at all times of the feelings of others. I was, in fact, the person I had been trained since infancy to be. For
so many years I had worn a mask, I was not, even at this moment, aware that it was a mask. As my life was collapsing, as my body was turning from muscle to water, and the cells upon which health and movement depended were dying by the millions, I remained a well-brought-up, courteous and considerate, upper middle-class child.

And, as the mask was impenetrable, as the wall was unscalable, there was no way for me to reach out for comfort and support, no way to share or have acknowledged the deep terror of the unknown, the agony of pain. I could not reach out, and I knew no way of letting in those who would help, those who would share, those who would acknowledge and give comfort and support. Whatever I must bear, I must bear alone. Whatever was happening to me, whatever my feelings were, however desperately I yearned for help and understanding in the face of these terrible things, none of this was reflected upon my expression or my demeanor. I was, I believe, a perfect patient.

This memory of emotional isolation fills me today with a terror far exceeding the fears aroused by a recounting of the physiological events of my disease. It is conceivable I could live through similar events again; it is inconceivable that I would be able to do so alone, masking my emotions, denying my needs (37).

In her book *The Horizontal Woman* Suzanne Berger (1996) also speaks eloquently of the cleavage of one's reality into life shared and life unsharable and how this results in a loss of self.

Chronic pain seems to starve the fleshy part of your soul and its generous perceptions. While self-pity persists in feeding it the wrong stuff. You can just sit there eating it, of course, but the room grows darker and lonelier around you with each meal, each season passing outside your life with banners, bells, and whistles. Because the preponderance of dark self-regard pushes others away, and makes a boring diet. Also a relentless dominatrix, pain makes you cringe from the constant self-referring. But because you do feel ruined, especially at first, it's almost impossible to do otherwise, though you promise yourself not to complain in front of others. However, the incessant effort not to bemoan fate, not to be openly anguished, makes for a drastic inhibition of the self, so that the voice attempting to be cheerful will come out sounding tinny, with a kind of empty brightness, like rhinestones. An effort that, I believe, pushes confined people back into themselves, alone at the table, the inner light and energy having been spent on the work of not appearing depressed, not letting self-pity show. Self-referring then is traded for self-effacement, not a fair transaction at all (49).

This self-effacement or backgrounding of the self can become so habitual that it makes it difficult to adapt to situations where more openness is desirable or even necessary. Part of the conversation between Karen and myself already quoted is relevant here.

Me: And it does [superficially] make you feel better about yourself, but, like you say, it creates that wall between you and other people when it comes to how you are really feeling.
Karen: Mmm, yeah and also, when you do finally end up with a relationship you do find it hard to show him how you are feeling. When you are feeling different you just always say sometimes that you are that person.

Me: Because you're so practiced at doing it. You do it automatically.

Karen: I'm professional at it [laughing].

This habitual distancing of the inner self can make it difficult to be as close as one wants to be in one's intimate relationships with partners and friends. It can even prevent one from having the courage to try to become intimate at all. In the following excerpt from *Mustn't Grumble*, Jeni Fulton (1995) writes about the conflicts she experiences in developing a more intimate relationship with a male friend.

The car has stopped now. The rain has stopped too, but everything is sodden and heavy. The fog still clings everywhere. Time has stopped because I can't get past the point at which the motorway divides for me. I'm frustrated by the whole situation. I don't want things to go on as they are. I'm weary of emotional dishonesty, of being on my guard, of not being completely me, of suppressing such an important part of myself, of behaving so inconsistently, at odds with the strong political woman I am. But is it possible anymore to be honest in talking affairs of the heart - or body, more's the point - when there's a fundamental insuperable barrier between us? The twisted, scarred and sagging deformity that I perceive to be me (88-89).

In their most serious form, the cumulative costs that a disabled person can incur by containing his or her emotions behind a wall of stoicism and good cheer can lead to an eventual crumbling of the wall and a collapse into emotional breakdown. Both Hugh Gallagher and Karen discuss this outcome in their own cases and believe it to be the result of years of suppression. Hugh speaks about it thus.

It was at terrible cost to my person. I repressed or denied everything. I had no feelings; at night, I had no dreams. No sex. I simply ignored pain and fatigue. I did not allow myself to get sick. I took risks and did things no sane person would ever do. I lived in terror of collapse, of fear that the world would see how hollow I was. I had a million friends but I could confide in no one because, in truth, I had nothing to confide. When asked about my handicap (as it was called in those days) I would reply, "I never think about it, never think about it at all." I continued in this desperate fashion, wracked with constipation and insomnia, until July 4, 1974. On that day, I bombed out of Super Cripdom. My body collapsed physically, and I plunged headlong into a deep and chronic clinical depression, which took me years to climb out of (Hugh Gallagher 1998: 246).
Karen also reached a time in her life when the façade collapsed.

Karen: [I experienced a] lack of confidence inwardly, but outwardly everybody thought I was this confident, well adjusted person.

Me: Yes, so that was part of that sense of, when you were around about 18 … you wanted to get out in the world and have a normal life and there seemed to be a lot of things getting in the way of that and your perceptions of that, but you buried that. You actually went on and pretended that everything was okay, but it couldn't continue. So, how did all that work out? For while you were able to make it seem like it was okay...

Karen: That was when it all came to a head, when I basically had my break down.

Me: Right.

Karen: It had to all come out then, basically. You can only cope for so long, pretend for so long and it all catches up with you. I tried to take an overdose, because I couldn't cope with it and that's when counselling came into the process and that was the best thing that ever happened. It actually got me on track, by teaching me … that it was all right to have all these feelings and these emotions and bits and pieces, but beginning to respect myself and not being worried about what other people think all the time.

I am four people when I read about such painful experiences. The first three are close to the surface and clearly and consciously affect how I react to these revelations. I am a researcher who is sorting data and reporting on a significant finding. I am a human being who feels sad and angry that some people have to suffer so much so needlessly. And I am a disabled person who can directly identify with the desolation and desperation and emotional toll that being invisible can exact. But, the fourth person only emerged when my disabled and empathetic self was shaking her head sadly while feeling relieved that she was one of the lucky ones who had not had to completely hit rock bottom. At this point I experienced a sense of dissonance and faded fragments of memories began to flicker in the background of my thoughts. For, although the narrative that I have stitched together to make myself feel whole acknowledges that I have experienced a great deal of pain. As Adrienne pointed out during our dialogue to explain why she did not wish to dwell on the losses she had suffered, "It's like picking at a scab. If you let it alone it will eventually grow new skin."

It shocked me to realise that I could hear of Karen and Hugh's eventual breakdowns and not immediately remember my own. I almost avoided the memories altogether, but my dual position as researcher and researched has often forced me to face the incongruities inherent in my self-storying process. Like Karen and Hugh, my emotional collapse culminated in a specific event which ultimately represented a turning point. But the process of breaking actually occurred in an agonisingly drawn out series of smaller fractures. It now seems like that time exists in another
world, a cold and lonely world in which all hope was lost. Climbing out of that kind of hole requires the creation of a whole new way of seeing the world and oneself within it and, for Karen and Hugh and I, a large part of this involved learning how to break the silence.

**Breaking the Silence / Letting Go of Pain**

In concluding this chapter, I bring two sets of reflections together. The first deals with breaking the silence, the second with strategies for living with pain. In relation to “breaking the silence”, the first point is that relatively few people in this study believe this to be possible or, in some senses, even desirable, given the costs. Among the ninety two people whose voices have been included in this study, those who preferred to “pass” on an emotional level were in the majority. In the minority, there were those who stated that it was vital to rid oneself of these feelings and get on with life, and, on the other end of the scale, a similarly small number talked about challenging this process of sublimation.

One of these was Hugh Gallagher and his experiences are worth considering at some length. When Hugh traced the pathway which ultimately led to his decision to be more open about his feelings and experiences, he points to the lessons he learned from Franklin Delanor Roosevelt (FDR). He initially began the project of writing FDR's autobiography because he considered him to be his greatest hero and role model. Yet, try as he might, Hugh could not successfully follow FDR's example and he began to 'wonder about [his] hero, FDR. Had there been anything behind his facade? To answer this question, [he] began the research that resulted in [his] book, *FDR's Splendid Deception.* Over this time he learned that FDR had 'dealt with the fact of his paralysis by means of total denial' and that '[t]he wreckage proceeding from FDR's closed mouth "courage" was everywhere' (208).

Hugh writes about 'a rainy, cold November Sunday afternoon’ when he sat in a car park and saw the parallel between himself and FDR in relation to how they dealt with the failing muscle control that accompanies post polio syndrome and how, as a result, FDR ‘died before his time, lonely, depressed, and exhausted’ (209).

It was there in that cold and rainy parking lot that I at last broke with the President of the United States. I would be goddamned if I would follow him, stiff upper lip, good soldier to the last. I would shout out my hurt to the skies, curse the fates, both mourn and celebrate my loss. FDR was a great man, a magnificent leader of world scale, but he was no longer my role model. He was Super Crip; I opted for human.

My feelings are mine; they go with the territory. People who love me will share these feelings, and, together, we will cope; more than that, we will prevail. This way lies survival. (ibid).
Karen also spoke of similar revelations when she told of her breakdown and renewal. Her reflections on her decision to break the silence were not as neatly expressed as in Hugh’s case, but were interspersed throughout our conversations. Her breakdown was a vital turning point that she returned to in the dialogues several times. At one stage, she commented, ‘You can only cope for so long, pretend for so long and it all catches up with you.’ Eventually she lost faith in herself and attempted suicide as, she said, ‘I couldn’t see myself going on like that ... but I didn’t know what else to do.’ Counselling helped her to realise that ‘it was alright to have these feelings’ and that she could acknowledge them and share them with others in comfortable and liberatory ways. She summed up by saying, ‘It’s still hard sometimes and I don’t always get it right, but, you know, I’m okay about who I am and I’m not ashamed to talk about what it means to be disabled.’

In touching on the need to speak out, Max Dashu (1986) writes about her ‘refusal to let her epilepsy be unspeakable. Or invisible; because even when its affects can be seen they are not identified or understood by most people’ (204). And Dai Thompson (1986) discusses the need to express our emotions because ‘even if the larger community would adopt totally fair and appropriate attitudes toward people with disabilities, this would still not eliminate the sense of loss, the frustration, and indeed the anger we feel just because we are disabled’ (79).

In considering different strategies for dealing with pain, I wish to touch on two connected, yet seemingly contradictory ways in which people can find solace in the face of disability. The first is encapsulated in the following dialogue between Adrienne and myself.

Adrienne: It’s important to know ones pain, but, you know, we take pain killers for a reason.

Me: We do.

Adrienne: I think that one of the things that I’ve learned that is one of the four noble truths of the eight fold path. I had this Buddhist friend for a while who kept telling me things and I picked up just enough to be appallingly ignorant [she laughs]. [This one is that] pain is inevitable, suffering is optional ...

Me: I know what that means now. I don't think I would have gotten that ten years ago, but I understand that really well, because I've learned the difference.

Adrienne: Yeah, and we can control our suffering.

What is being discussed here is our belief that there is, at least to some degree, a choice in relation to how we deal with our pain and losses. And, I believe that part of an effective
strategy would combine the capacity to be more open with the ability to let go of certain expectations and negative feelings.

The second is, in fact, the possibility of “letting go” and “getting on with life”, a response touched on at various points in this chapter. In admitting this, I, thus, remain open to the idea that some people who report that they have let go of their negative feelings have actually done so. One such person is Chris Baker who responded to my call for participants by telling me his story in a series of emails and short stories. When I asked him the question: “How did becoming ill/disabled affect the way you felt about yourself?” he replied as follows.

Initially, it nearly finished me. I was suicidal for a few weeks, before I found out what was happening. My identity was based on the image of a tough ex-bushman, resourceful and able to handle any of life’s vicissitudes. It was also based on a sort of Sir Galahad rectitude and of course the first thing the MS did was rob me of both. My physical prowess? Gone. My manly grace? A fast-diminishing joke. And to make matters worse, my partner, in whom I’d invested most of my emotional energy, left me, finally succumbing to a burgeoning schizophrenia. Her departure had nothing to do with my condition, which serendipitously waited until the day after I helped her onto a bus to her home town before visiting on me a collapse where all my energy simply drained away at the speed of a washbasin full of shaving water with the plug pulled, and left me sitting out the back of my flat wondering what the hell had just happened.

These two events coincided most happily with the end of a year’s spiritual instruction, based around the premise ‘be happy’. This, of course, was as simple as it sounds, but it took me ten years to work it out. In the process, I devised the strategy by which I’ve coped with the disability wrought by the MS. It took me that long to get my ego under control, and to grasp the idea of the law of cause and effect, and the concept of emptiness.

I also had to deal with the grief of losing the parts of my life that the MS trashed. It was this process that finally brought me to the point where I was able to see my disability as a blessing, as a positive rather than a negative condition, and I can see now that this positive attitude was central to my handling of the disease and the wreckage it made of my old life (Chris Baker 2002: 2-3).

For many of the participants in this study, however, the pathway to freedom from feelings of loss has not been so clear and often, as has been demonstrated throughout this chapter, the appearance of “coping well” rests on an elaborate process of self-denial. When Karen and I first engaged in the conversation about hiding one’s pain, I attempted to express the difference that I perceived between coping well and self-denial. I would like to include it here, verbatim, as I still lack any better way of saying it as expresses what I perceive as different states, one healthy and the other very damaging.
There are very positive things that we've learned, very deep things that are going to help us through life and they make us understand life even better than people who haven't been through them. But, there are other coping mechanisms that are probably unhealthy because they are about burying things and concealing your deepest feelings. So, I think, on the one hand, there are going to be things that I discover through talking to people and it's like, yes, yes, and I'm really inspired and I think, yeah, these are the things I want to develop, and there are other things where I think we find ourselves behaving in ways that we're uncomfortable with, but we don't know how else to behave because that's what society expects from us. That's how we have to behave to fit in.

Telling the difference, however, is often extremely difficult. What is clear, however, is that, because socially sanctioned forms of “coping well” largely require the submersion of emotions, disabled people are offered a false choice which obscures that dealing effectively with loss involves an acknowledgement of the pain. Both Chris and Adrienne, however, through developing a spiritual understanding of the role that pain and loss play in their lives, demonstrate that it is possible to bring pain to the surface and, over time, to let it go.
CHAPTER SIX

The Loss of Independence

Such dependency is much more than simple physical reliance upon others, for it begets a kind of lopsided social relationship that is all-encompassing, existential, and in some ways more crippling than the physical defect itself. It is not so much a state of body as a state of mind, a condition that warps all one's other social ties and further contaminates the identity of the dependent. (Robert Murphy 1990: 199).

The loss of the ability to do things for oneself appeared to be the most pervasive theme of all when it came to the losses talked about by disabled people. The nature and extent of the loss depended on a number of variables including the severity of the impairment, the kind of support system already in place, the time elapsed since the onset of disability and whether the impairment developed slowly and involved an unclear prognosis or occurred suddenly and remained relatively stable. However, there were certain feelings attached to the experience of becoming dependent on others that appear to have occurred across the board and this chapter will begin by sharing these sentiments. Most fundamentally, as with any identity-based loss, there was the experience of transformation, from being a certain kind of person to becoming someone in possession of a less desirable sense of self and a disturbingly different life. The most concise description of these losses come from the published autobiographical and written statements as these people had the time to present their experiences in narrative form. I quote from a number of them below.

It seemed as if I were watching helplessly as I disappeared and a sickly, dependent stranger for whom I had no respect was taking my place, stealing my hopes and dreams (Melissa Anne Goldstein 2000: 96).

I was resentful at having to depend on someone else to do what I wanted to do for myself … I was losing my old self - the way I controlled my body, the way I conducted my physical being. My daily routine - not only closing windows, but getting out of bed, getting dressed and washed, doing dishes, cooking and going to the john - seemed nearly impossible. I had taken for granted the old ways of doing things and only appreciated the simplicity now that drastic changes were necessary (Marjorie Wagner 1986: 59).

But my body, which I had called myself, had changed dramatically from autonomous to dependent, from strong to weak, from rapidly moving to completely immobile. I had to rely on others for even my most elemental functions and activities - even those that belonged in the bathroom. My spatial existence seemed more like that of a sack of flour than a human being …
I had been thrust backward in the developmental scale, and my dependence was now as profound as that of a newborn. Once again I had to deal with all of the overwhelming, degrading conditions of dependency that belong with infancy and childhood - at the same time that I considered myself a mature adult (Arnold Beisser 1989: 22).

From being athletic, I was now disabled; from being a wife and mother, I was now solitary; from being able to relate to others on equal terms, I was now patronised; from being a public servant responsible for assessing the disadvantaged in order to establish their eligibility for state benefits, I was now one of those disadvantaged people; from being an independent adult used to making her own decisions, I was now treated as a child (Lesley Tyzack 2000: 1).

Even though I am suggesting that the written word makes it more possible to succinctly outline the details of one’s distressing transformation into the realm of disability, it is still far from easy because it touches on an extremely painful experience. When I first hurt my back I was aware of having an impairment but not a disability because, as far as I was concerned, it was a temporary condition. Certainly, it was extremely frustrating to find my life as I had been living it so abruptly halted and I hated having to rely on others for almost everything. But, initially, this did not affect my identity as such and did not constitute an overall loss because I did not and could know that I would still be largely immobilised and in high levels of pain over a decade later. My horror at the loss of my independence came upon me gradually as my former life shrivelled and eventually died, as the people who had originally come to my aid became resentful, and as this necessitated the unthinkable but only solution of moving back to my parents’ home at the age of thirty two.

I had been so proud of what I had achieved. I had made a life for myself which was heavily based on physical strength and independence. Now I was “back there” again, where back there referred to more than just the physical location of my childhood home, it was also indicative of a loss of autonomy, the loss of a certain status that comes with adulthood and the achievement of certain objectives, and the loss of the ability to engage in life freely without having to plan every move like a battle campaign and without having to feel heavily indebted, guilty and ashamed in response to needing so much help to attain what seemed, in comparison, a very poor quality of life.

The Self Immersed in Unacceptable Need

The terms most commonly used to express the feelings which accompany becoming and remaining dependent on others are “anger”, “resentment”, “frustration”, “shame” and “humiliation”. Although these emotions have many causes they are all linked in various ways to the infantalisation process. When treated like a child, it is natural to react with anger, frustration
and resentment. When feeling like a child, shame and embarrassment are understandable responses. Many people wrote about their feelings of becoming child-like in their dependency.

His mind, proud and ambitious, was still there; but the body, the means of serving his pride and ambition, was gone. In its place was the curious soft, pudgy body of a baby - fully as helpless and as pink but lifeless (Hugh Gallagher 1998: 150).

Now you are a body on one of eight high metal beds. Lying under stiff sheets, eyes fixed on the door, feeling the rubbery chill, you are four years old again (Inga Clendinnen 2001: 23).

I felt like a helpless baby having to rely on everyone for the simplest things (Jane, written story: 2).

Infantalisation is also something that is imposed by others and, in this vein, Albert Beisser (1989) writes about his redefinition as an infant.

Once, the six-year-old son of a friend put the whole matter in a nutshell. He had great difficulty categorizing me, for I seemed to have many of the privileges and responsibilities of an adult, but on the other hand, everything had to be done for me, as with a child. He did not know what to make of me. Finally, with a special joy that comes from insight and illumination, he said, "Oh, you're a big baby!" I did not share his joy over the category he placed me in, even though it did seem to fit.

I had been thrust backward in the developmental scale, and my dependence was now as profound as that of a newborn. Once again I had to deal with all of the overwhelming, degrading conditions of dependency that belong with infancy and childhood - at the same time that I considered myself a mature adult.

I did not adjust easily to my new dependence, and despised giving up what I had won years ago in long-forgotten battles. The baby and the man were in conflict, and the conflict was heightened by the many ways that other people treated me. Some people were interested in the dependent baby; others found the adult part, my head, more deserving of attention. Some seemed concerned with controlling what they considered the unruly child, while others wanted to nurture a helpless infant.

Nurses and attendants often talked to me as if I were a baby. If I became soiled through no fault of my own, they were likely to say, "Naughty, naughty," or "You've been a bad boy." Some people were so perplexed that they simply fled in despair. None of these attitudes helped clarify my confusion about how I thought of myself (22).

This process of infantalisation can lead to the disabled person being seen as child-like in other ways, for example, incapable of making appropriate decisions. Albert Robillard (1999) writes
about the response he was given when he would not follow the instructions given by his therapists.

After I had explained that the voice panel board would not work for me, I got the distinct impression, mainly from facial expressions of the therapists, the salesman, and my wife, that I was being willfully obstructive in rejecting the machine. "Don't you want to help yourself?" the salesman asked with a sigh. Divina added, "He is very stubborn." Still, I insisted that the machine was inappropriate (128).

The whole tone of the interchange locates Albert as a child who is being chided for his lack of cooperation. He is being a 'willful' rather than an obedient child and his own perceptions of what is best for him are not being trusted. Chris Baker (2002) touches on similar ground when he writes about adapting to life in an institution. He quickly realises that, in certain situations, the willful child is not acceptable.

I'm not silly. I know when to shut up, and I manage to act contrite. And helpless. They like helpless, and despite appreciating independence, are nonetheless alarmed and discomfited by it (4-5).

However, although disabled people are often thought to be childlike this does not mean that their process of seeking help is as straightforward as it is for children. Jacky puts it thus.

Other people did, and still do, treat me in a childlike fashion - all happiness and good intentions - until you may perhaps want or need something (written story: 2).

The social forces which affect what happens when disabled people need to seek help will be explored in the following section.

Seeking Help

Being able to negotiate the process of seeking and managing the assistance of others is fraught with difficulties. Often people who become disabled need to rely on friends, family members and even strangers for help and this puts pressure on relationships and often strains them. Others are given necessary care by paid workers and they in their turn face different problems which will be discussed later in this chapter. In either case, learning to accept help can be seen to be part of the process of coming to terms with a more limited physical capacity, a very painful part, and is often avoided if at all possible. Therefore this section will begin with the statements of those who have preferred to live more limited and/or painful lives than to ask for help.

Throughout my dialogues with Anne, it became apparent that asking for help was not an option.
Anne: I reject help at the rate of knots and I find it very difficult...

Me: So, you still do?

Anne: Yes, oh definitely. I've never, ever been able to do that. Because, I can function. Look, honestly, there's never been a time... even when I was on crutches and bedridden, I suppose I was still trying to function on my own. And crawling... I don't know if I told you last time, on my knees [we talk about how we both ruined our knees by trying to be independent].

Kevin Hitchcock (1998) also expresses an extreme aversion to asking for help.

I hate relying on other people. I feel inadequate. I can't get away from that feeling or overcome it. My stubborn insistence on being independent won't allow me the humility to readily accept the help of others (157).

Recall that Melissa Anne Goldstein (2000) wrote that ‘asking for help was an overwhelming obstacle for me then, and even now, though to a lesser extent. It seemed a sign of weakness and made me ashamed and embarrassed' (111). Similarly, Hugh Gallagher (1998), as it became clear in Chapter Five, avoided asking for help until his body and emotions completely broke down from the effort of trying to remain independent and stoic. He expresses it thus.

In the bad old days, I tried to be the “heroic” crip. I asked no one for help. I was determined to get into cars without help. I would transfer, all by myself, onto strange toilets even if the transfer was dangerous. I would lift myself into hotel beds even if the effort left me breathless and my muscles cramping. I insisted upon traveling alone; I even flew alone around the world. The tension and anxiety caused by this made travel a terror (203).

These feelings are very close to my own experience. In the following dialogue with Peta about the need to reciprocate, I talk about my own experiences where too large an imbalance in the "give and take" of my relationships made it impossible for me to ask for much needed help.

And now finally, in the last 18 months, I have moved into town. I'm right in the middle of town and I can do just about everything I need to be able to do for myself and it's just wonderful. But, when I lived out in the bush I needed to rely on others to go anywhere or get anything. I had to travel lying down in the back of a car and I needed to ask people to pick stuff up for me at the shops. And sometimes I'd rather starve, basically. It came down to that, because it was all one way and I was trying to balance it out by giving to other people and not taking anything unless my need was urgent.

It is still very painful for me to remember the time when my situation was so difficult that I would rather starve than ask for help. Even more disturbing is the recognition that, if I were thrown
back into that strange mixture of isolation and dependency again, I would still rather starve than risk tipping the scales too far out of balance. For me, consequently, the solution lay in creating an environment which has allowed me to be as independent as possible. But, it is conceivable that an increase in my level of disability could force me to suffer from similar losses in the ability to reciprocate. This possibility lurks as an impending source of terror.

Many others, however, talked or wrote about having come to accept the need for help. Leslie Tyzack (2001), in her essay analysing her own experience of identity loss and reconstruction, writes about having to learn 'new norms of behaviour, which differed in many ways from the behaviour expected of an able-bodied person' (2). As part of this adaptive process, she writes:

For example, I often needed help in day-to-day tasks, and I had to learn to ask for this help in a way that did not frighten or alienate people with little or no experience of disability. Once I had learnt these skills, I was ready to face the next stage in my development (ibid).

In an extensive dialogue with Nancy, which focused entirely on the issue of independence/dependence, she talked about her recognition that, due to the extent of her spinal cord injury, she needed to quickly accept her need for help.

Nancy: Almost from the beginning, when you realise that everything has got to be done for you, I think there's a point where you say to yourself, I have to accept this. This is the way it is, so I've got to accept it. I would say after that, once you've done that major brain washing thing to yourself of, this is the way it is, this is the way it's going to be, you stop thinking about it. That's the way it is. But, even accepting that's the way it is, what I used to say was ...okay, I accept that you have to do everything for me physically. That's obvious. That's fine. And I accept that. But, when it comes to my mind or my spirit, keep off the grass. They are very much mine.

Nancy's acceptance was conditional. She would let go of her body as a colony over which she could no longer maintain direct control. But her way of thinking and her autonomy was not to be interfered with in the process. This distinction will be discussed in more detail in the concluding section of this chapter.

Both Hugh Gallagher (1998) and Melissa Anne Goldstein (2000), although initially very resistant to seeking support as demonstrated above, wrote about how they eventually learned to accept help, Hugh by employing people to provide assistance while he travelled and Melissa by developing a whole new view of interdependence and her value as a friend. Hugh writes:

Now I no longer have the strength to pretend that I can live independently on the road. I need help with everything. If I am to travel, I now must travel with a helper. To my great surprise, this has made travel not only easier, but also fun. Over the years I have been
fortunate to have had as helpers some excellent guys. They have been not only employees, they have become lifelong friends (Hugh Gallagher 1998: 203).

Melissa puts it thus:

Most important, Evelyn helped me to understand that I could accept assistance from others without diminishment of self, because I could still help others, even if not as I had before ... I could still enjoy rich, full relationships that included giving and receiving on both sides. Possessing the knowledge that I could contribute to others was of paramount importance to me. I could still be the kind of person I respected. I could let go of the shame I had been carrying with me these past nine months. I also felt more secure; I no longer feared that people would abandon me.

Though this was a harder lesson for me to grasp, I learned how essential it was for others in my life to be able to help me. Their need to give was as deep as mine. They, too, felt powerless when confronted by my illness (Melissa Anne Goldstein 2000: 124).

I would argue that the differences between these two methods of coming to terms with being dependent on others are indicative of the overall differences that exist between those who rely on paid carers and those who depend on the goodwill of others. Ultimately this distinction had such a powerful effect on how disabled people conceptualised and negotiated their need for support that it demands a lengthy consideration in a section of its own.

**Remuneration Versus Goodwill**

Prior to engaging in the dialogues and reading the autobiographies, I was not familiar with the experiences of anyone who managed their need for care with the help of professional assistants. My only experience with paid carers had been during the times I spent in hospital, which included three stays of around two weeks in general hospitals and one month spent in a rehabilitation facility. I certainly did not enjoy the institutionalised life, but each time I was admitted to hospital I can remember feeling a great sense of relief that I would no longer be a burden on my friends and/or family. I felt more comfortable about receiving help from those who were paid to give it to me than I have ever been able to feel when reliant on the kind of informal support which is based, as one participant put it, on the "goodwill" of others. Having now spoken in depth with three people who rely almost solely on paid personal carers, one who lives in an institution and two who receive assistance in their homes, I can see that there are enormous differences between these people's experiences of dependence/independence and those who, like me, have had to rely almost exclusively on informal arrangements.

In this particular sample of the disabled population, those who procured professional carers were primarily those who were or had become wheelchair users due to the paralysis which
accompanies conditions such as spinal cord injuries, advanced Multiple Sclerosis (MS) and some congenital disabilities. These disabilities are extremely severe and offer no opportunity for the person to "pass" as able-bodied in an attempt to avoid asking for help. It would appear from this particular study that, due to this degree of severity, the identity crisis is also extreme as the adjustments required are enormous. However, it would also appear that, once this adjustment has been made, the new identity and the level of autonomy achieved can eventually be much more favourable than those whose conditions seemed in many ways less dramatic. I will be suggesting here that part of the reason for this superior level of adaptation is linked to the battles these people won to secure effective assistance from paid carers.

Lesley Tyzack (2000), for example, became so severely affected by MS twenty years ago that it was agreed that her life was not worth living and she was granted permission and the means with which to end it. It was at this point that she realised that her 'will to live was too strong' and from that time forward she set about creating a meaningful life for herself (1). Her initial experiences with seeking support were horrendous. Originally she became bedridden in her marital home and she describes her experience of relying on the informal care of her family in the following dialogue.

Lesley: …my husband didn't want to be responsible for my care.

Me: So, your husband didn't want to come to the party at all.

Lesley: He resisted it quite a bit. And it was just a really difficult time. There was a lot of friction. There was one point when I was in bed the whole time, barely able to get out of bed... you know, just able crawl to the toilet and that's all. I couldn't feed myself and my mother-in-law came along at that stage and helped give me meals, but she wasn't actually the motherly type...

Lesley lived in Australia during the early years of her illness, but when she eventually developed quadriplegia and ended up in a series of hospitals and nursing homes, she felt that she would receive better treatment in New Zealand where she had spent most of her life prior to marrying an Australian. She was aware that the conditions under which disabled people live were more favourable in New Zealand due to both the superior formal care arrangements and social attitudes in general. She believes that in New Zealand people ‘on the whole, have a much greater respect for autonomy than Australians’ (private email correspondence 2/12/01). She now expresses her state of autonomy as follows:

Lesley… for the last three years now I have had just as much freedom and independence as any other adult New Zealander, mainly because, along with a lot of very high technology equipment, I have individualised funding, which is a lump sum fortnightly payment from the health department which I use to employ and pay my personal carers (ibid).
Reaching this state of independence, however, did not come easily and, initially, the paid assistants in charge of her care were the nurses who worked in the institutions that Lesley was forced to live in at times in South Australia. When talking about the oppressive atmosphere, the lack of freedom and her eventual demand for autonomy, Lesley expresses it thus:

Lesley: [It] was really what I would imagine a prison was like. If a prison is worse than that, I feel really sorry for the prisoners.

Me: Oh really?

Lesley: You were told what to do and when to do it. And they'd base it very much on what they did and you had to fit in with their routines.

Me: How horrible.

Lesley: And, I was able to stand up and say, no, that's not what I'm going to do. This is the way I'm going to do it and this is what I want to be done.

Nancy told similar stories of institutional life prior to the changes brought about by the disability rights movement. Nancy, however, has lived in an institution since an accident thirty years ago which resulted in an extremely debilitating spinal cord injury. She also compares the old style institution with a prison and says that:

Nancy: I felt as though I was being punished all the time. Well, probably what I've described to you sounds like punishment. It certainly felt like it.

Me: Well, it was.

Nancy: And the other thing I used to say was, hang on, what's this all about? I didn't commit a crime. I only had an accident.

Like Leslie, however, Nancy fought for her right to choose how she should be treated and how she would spend her time and she describes her demand to be treated with respect and her transition to autonomy as follows.

Nancy: Yeah, well, look at it like this, Rose. This is the way I see it. They are paid to do a job. What's their job? It's being my hands and feet but not my head.

Me: Exactly. And that's where you have to draw the line, isn't it? That they shouldn't, just because they're doing those physical tasks, think they own your... will? They need to know that you are still in charge in that way.
Nancy: Well, I've probably got it to an extreme … I probably don't get a very good name for it. I don't really care. I don't mind. Because of the treatment I got in the early years here, where you didn't have a voice at all. As soon as, gradually,... and I think I said to you before, 1981, the year of disabled persons, that was the year that it became trendy to be kind to poor crips.

Me: Yes, right.

Nancy: I said that before I believe. But, anyway, after that, gradually, you gradually found your way into working for the militant disability crowd or doing other things, whatever, and then going to university. Gradually, gradually I got more and more autonomy until the national government, about ten years ago, they brought in the new health reforms. Suddenly, it was not only trendy, it was desired. Where are all meant to be responsible for ourselves.

Karen spoke to me of a different battle to gain autonomy. She was born disabled and, when she became an adult, she wished to leave her family home to begin a life of her own. She was ineligible for the supports which were given freely to those who were covered by the accident compensation legislation brought into existence in New Zealand back in the 1970s and, therefore, she needed to fight for special consideration so that she could be granted the assistance she required to live independently. She is now funded by the same government body which Lesley refers to which enables her to manage her own carers. This has enabled her to be independent enough to gain employment, to have a happy marriage of twelve years in which the responsibility for her personal care has not fallen to her husband and to employ and organise her carers in the way that is most suitable for the needs of she and her husband.

In the following excerpt, Arnold Beisser talks about how much better he feels about the assistance he now pays for, in comparison to that which was given grudgingly by informal carers.

I used to feel crushed and humiliated when I needed help from someone and they did not want to do it. I would blame either myself or them. But the sting I felt has now diminished. Getting help for my needs is more of a business transaction, and I no longer feel like I have to act like "the brave little soldier." The change also became evident to me when I could interview prospective personal-care attendants and discuss their duties without embarrassment (132).

Most of the people I read about and talked to did not have paid support and, therefore, had to rely on gaining the help of friends, family and even strangers. Many of them discussed the issue raised by Arnold Beisser above when he wrote that he felt bad about needing help with something if 'they did not want it done.' Craig, who refers to his impairment as blindness, writes about this as follows.
You go to a Church group. They will be safe. The youth invite you to an outing at the beach. No problem. You arrive at the beach, singing choruses “Oh Happy Day, Oh Happy Day, when Jesus etc.” A nice young thing offers to assist you down to the beach. “Thanks, are you sure?” “Of course, I don't mind.” The happy young people run on ahead. Turning back they shout, “Come on Sharon, hurry up.” “I can't hurry, I've got to help him,” she says in a brassed off tone of voice. Shrink shrink, I wish I'd never come. Why did she say she'd help if that's the way she really feels? [written story: 6].

Aaron also talks about the discomfort that arises if the help he needs is not given freely.

Aaron: Well, no, I don't have a problem with asking for the help, but I have a problem with my partner that she's obligated to do everything. And that makes it very difficult. It puts a bit of a strain on the relationship at times…

Me: Yeah, it just pushes it out of balance a bit, doesn't it?

Aaron: I think though that… I think it's the expectation that they build up in their mind that they're going to have to do it. So, me going out and doing something is just an extra burden for them and, you know, that's always the concern for me. You know, you don't want to put that kind of pressure on.

Me: No, you don't. But it's really hard not to.

Aaron: You know, I don't have a problem with things that are done voluntarily, but I feel that there are times when my partner feels it's really not a choice for her, she has to do it. And that's difficult for me.

Even help that is given voluntarily can feel uncomfortable. When Alana Arnot (1998) left an Australian hospital after many months of rehabilitation for her spinal cord injury, she had to rely completely on her husband. She writes:

Nigel worked with me methodically, but I could see the strain in his face at times and knew he hated seeing me so incapacitated. I cried a lot that weekend. It was so humiliating and frustrating having to rely on someone else for everything (175).

Melissa Anne Goldstein (2000) also writes about the unease she felt at the thought of asking her friends for help.

But asking for help was an overwhelming obstacle for me then, and even now, though to a lesser extent. It seemed a sign of weakness and made me ashamed and embarrassed. I was also protecting my friends, keeping them from worry. And though I did not openly
acknowledge it, even to myself, a tiny part of me, buried deep, felt that I must maintain a healthy facade, or I would lose my friends (111).

And, as Chris Baker (2002) wrote to me about how he was settling into his new life in a nursing home:

Ellie is most welcome here. She's able to eat meals here & stop over if she wants, & Sam the dog is also able to visit, leaping & slithering around the room. It's good to be able to stay friends with Ellie, a situation that was seriously endangered by her having to care for me (cf yr words about friends & family) [personal email correspondence, 7/8/02].

The above reference, once again, points to the difference between paid care and the reliance on loved ones and others. Needing to rely heavily on one's intimates obviously puts a great strain on most relationships. Adrienne talks about this in the following dialogue. She contemplates what it would involve to live alone, without the help of her partner who has taken over the shopping, cooking, house cleaning and laundry.

Adrienne:... and it's come to the point where there are so many things that I just can't... I don't know... can I ever live alone again? What does it mean? I mean, yeah, I can imagine managing an attendant, but I'm not very patient in myself and the willingness to just put up with shit that is required to communicate what one needs done to another person …

Me: Oh yeah.

Adrienne: And so, that's been really yuck. Yucko!

Me: Oh, I know. It is.

Adrienne: Yeah, there is an interdependent ideal, but always, always, there's that question in the back of my head, will my partner leave me? Am I asking too much?

Kenny Fries (1997) pays someone to do the housework, but still feels that his lover is burdened because of his needs.

Since living with Kevin, I've made sure I have housekeeping help other than my lover. But still the physical imbalance between us sometimes takes its toll. Most people who help the disabled do so in the hope of cure, or at least to alleviate a temporary physical situation. I'm afraid that when a disability is chronic not many will stick around for the long term (216).

As Karen, who battled successfully to attain the assistance of personal carers, puts it:
Karen: I mean, I've got a perfectly able-bodied husband, but he is not going to do my personal care.

Me: Yeah, and the expectation here [in Australia] is that you don't need support if there are people there, whether it be your parents or your siblings or your partner … or your friends. And you can't run your relationships and your friendships like that.

Karen: And as much as they love you and want to be with you, they wouldn't do that for the average wife.

Karen's husband was able to marry the independent woman he met and fell in love with. Karen implies that, if their marriage had necessitated that he take over her personal care, it would not have been acceptable to either of them.

Whether the assistance one receives is paid for or not, the manner in which this help is received is an issue for all disabled people. Gratitude was talked about by many of those in the sample as an extremely problematic issue. The next section will seek to outline the dilemma which disabled people report in response to constantly being in need of assistance.

**Graceful Appreciation or Irrevocable, Soul Destroying Obligation?**

"Just stop saying sorry and thank you." [She] is angry with me, but I don't know how to stop the tears that are pouring down my cheeks. I especially don't know how to explain to her how these words define my current experience almost perfectly. I am so sorry for being such a burden and for not always being able to hide my distress and I am so grateful that she keeps helping me and does not reject me altogether. But, I know that any attempt to explain things better will damage our dying friendship even more than my tiresome sorries and thankfuls. I eventually manage to stop crying and say "Okay..." biting down hard on my inclination to add, "I'm sorry" (excerpt from my diary, 22/04/91).

Recently, I have been trying to explain to my partner and my friends the revelation I experienced about gratitude when Susan, one of my participants, brought up the following issue in one of our dialogues.

Susan: I just emailed someone at work - "I had a book recalled from the library. If you are going over today, can you take it?" And I read my e-mail back after I sent it and it says "[Terry] dear, sweety, honey, light of my life, please, if you are going to the library..." and it's just a joke kind of thing. But, it's not really.

Me: Yeah.
Susan: You have to keep saying it to people and it's not fair. ...It's a dent on ... not just your identity, but on your whole sense of independence. Why should I have to be nice to people that I don't really want to be nice to?

Me: Exactly.

Susan: Just to do normal, day-to-day things that anybody else takes for granted ... It's the dependency... just the dependency on the goodwill of other people.

Susan works in an environment where certain parts of her workplace are inaccessible or very difficult to access and she has been provided with no supports to help her with the tasks that her disability makes difficult or impossible. This forces her to be reliant on the goodwill of others where she is thrust into a state of constant gratitude and apology as a result. What I realised from this conversation was that those of us who are reliant on goodwill are forced to inhabit a space defined by irrevocable obligation and the unremitting need to show and feel gratitude. When I tried to explain this to my partner and friends, it came out sounding like I was ungrateful and that my deep and sincere appreciation had been a pretence. But, what I am trying to say is not that I am ungrateful. It is that I wish I were in a position where gratitude was no longer so necessary. And, apart from having my impairments magically disappear, the only way I can see this being possible is in the creation of a new social situation where formal support structures are more accessible and the attitudes towards interdependency are not so heavily reliant on identical forms of reciprocation. This is, however, a topic for the next section.

Following the above mentioned dialogue with Susan, I began to code for “gratitude” as a dimension of the larger category of “dependence” and it became apparent that a great many people had experienced similar feelings. Those who had relied on paid support and were at the mercy of institutions resolved the issue by refusing to be grateful at all. As Nancy was already quoted as saying in relation to demanding her rights very firmly:

Nancy: I probably don't get a very good name for it. I don't really care. I don't mind. Because of the treatment I got in the early years here, where you didn't have a voice at all ... because of the way I started and the way I was treated then, there is a voice inside me that says, no one is ever going to do that to you again.

Lesley also speaks about the injustices she suffered and how she went through a stage of refusing to be grateful at all.

Lesley: It's hard to get used to. I don't know how you find it, but nowadays I have my own funding and my own carers and they've mostly been with me for a long, long time. And it's just a very good relationship. They do things for me and they'll even go the extra mile and I pay them and I don't have to be grateful for it. But, at that stage, it was how grateful you were supposed to be for people doing things for you. And, even when
people were paid, they were paid by another agency which gave you the impression that they thought you were taking advantage of it and they didn't want to do any more than they absolutely had to.

Me: Oh right. So you had to be grateful even for that.

Lesley: Yes.

Me: Just the fact... and that's a real transition phase, isn't it? That whole phase from feeling like... I don't know... the position where you really feel that you need so much and you have to be grateful for getting anything, to thinking of it as a right and a form of your own...

Lesley: And, I really object to that, and I refused to be grateful. I refused to be grateful for anything. I think I put it in that essay that I thought I had to learn to deal out my thank yous.

Karen, who is also in receipt of formal assistance expresses a different, although related form of restructuring in her relationship with gratitude.

Karen: … that's what the counselling taught me, that everything you do in your life doesn't have to be for everyone else. She said I was one of these really bad people. She tried to get me angry one day and I couldn't get angry because I'd always been taught that I should be grateful for what you get … and when I say grateful for what you get I mean people helping you or... don't get me wrong, I'm very grateful when people help me and things like that, but it was kind of like you forgot to stop and think that it was nice of them to do that for you, but you needed this done because you needed it... she taught me that it's okay to go out and do things and do them for yourself, not just to make everyone else happy, you know. That was really hard...

Karen's insights about her own situation deal with the general reaction one feels towards always being in need, such that it is possible to feel that you have no right to do things for your own pleasure. Hugh Gallagher (1998) also writes about his relationship with gratitude before he changed his feelings towards being incapacitated. It is part of his third person account which was quoted from extensively in the preceding chapter on self-silencing.

He was pleasant and cheerful, thanking them for taking the time and going through the additional bother that his handicap had caused them. He did not feel very much like thanking them - he was tired and it was late, and there was really no excuse for taking 15 minutes to unload him and his chair from the plane - but he did so because he knew there would be other times, other nights, when he or some other handicapped person would cause healthy people some unexpected and unlooked-for burden. It is one of the obligations of the handicapped to be meticulous in thanking people for little favors …
After 25 years, he had found that these favors were given only when they cost no sacrifices. This was why he had worked so hard to gain such physical independence as he had. This was why he had worked to obtain his money and position. Money could not buy his physical independence, but it could buy physical assistance on which he could count. There was a difference - a substantial difference, he knew - between the reliability and relationship between a chauffeur hired to drive you to work each morning and a neighbor who volunteers to assist you in time of need. He first learned something of this when he returned to work. There were five steps into the building in which his office was located. The first several mornings, people were kind, assisting him up the steps. After the first week or two, he noticed the same people tended to use other entrances into the building in order to avoid the effort (160-161).

Suzanne Berger (1996) also writes a compelling testament to what she refers to as 'the patina of bastardised gratitude' that one feels toward 'the huge beastlike kindness'.

Someone brought food to someone who couldn't get food: human to human, an act of kindness, appeasement, and generosity, all of which the world is known to badly need, to put it mildly. Gratitude is expected, but no, this one on the floor … feels like a dog that has been fed and must then lift moist eyes upward in thanks to its owner … But it's as though food has been thrown to me: I can't complain, must try to feel always always always, gratitude for the big beast of steady kindnesses which has come to the door.

And so a certain patina of bastardized gratitude becomes the currency of dependency. Upon receiving both "favors" and necessities, it is expected. To keep peace, one must act grateful: the etiquette is as carefully laid out as in the old Emily Post. Gratitude is the good behavior extracted from the recipient of multiple kindnesses: a form of bitter payment between adults, who - while honorable and fair-minded - are trapped. As time goes on, giving gratitude becomes a labor in itself, when one person is always doing and the other receiving. It stinks like old broccoli. As years of "unableness" continue, gratitude makes the relationship between donor and recipient a briar patch. Soon the whole house is filled with one person's extreme gratitude, gratitude in every corner, until all that is given stands, with tusks center stage and shining, demanding notice, notice, see how grateful you should be.

The cosmic issue is that the previously autonomous person would like to reciprocate, would like to perform all those "kindnesses" for her/himself. I wanted to select my own clothes, drive myself, buy my own clothes, buy my own canes, my own presents for others; I couldn't. So sometimes the real wish was to say in moments of excruciating bathos: Take me out and shoot me or leave me by the side of the road, instead of, Thank you, thankyou, thankyou again. Unless a couple is sophisticated in the convoluted art of tactful tending, beyond any usual earthling capacities, the negotiation of acts of daily care takes over, gobbles affections, equilibrium, and harmony. Though no one is ever at fault, I know it is harder for the recipient - who should feel unpinched
gratitude and doesn't, and becomes knotted with subsequent guilt. There is no choice, in extremis: one needs the huge beastlike kindness (92).

Challenging the Norms Defining Need and Dependency

What happens when a person's life is governed by the "huge beastlike kindness" which demands endless gratitude, when the transition from able-bodied to disabled necessitates a regression, either self-defined or inflicted by others, into infancy, and when one's anger, frustration and shame become key features of one's identity? In many cases the response may eventually be one of epiphany questioning the authenticity and appropriateness of the ideology of individualism which underlies the ideology of independence in the first place. As Marjorie Wagner (1986) writes, the feelings of 'pain' and 'worthlessness' which can result from being in constant need actually stem from the kinds of social values which classify certain dependencies as unacceptable.

It is unpardonable in an individualist society to fail to be seen as self sufficient. Our society values a false sense of independence which results in pain and a sense of worthlessness for women and men whose capabilities have been ignored and whose potential has been uniformly underdeveloped. Yet, independence does not truly reflect anyone's reality. As a species, we are emphatically interdependent. Disabled people cannot be independent, not because we are pitiable or helpless, but because we are human.

Americans are particularly unmindful of the many persons on whom we daily depend for survival. A market economy - as a nexus - obscures this fact. Moreover, class relations are hidden by the ideology of individualism. We firmly believe that if we are able to purchase the goods and services we are not able to produce for ourselves, we are free of dependence. Conversely, if we are not able to buy them, we suspect we do not deserve "charity". Those who are able to purchase a false sense of independence are revered and are a measure by which the working class evaluates its members. The fact that some grow rich at the expense of their employees is conveniently ignored, while people who are systematically disadvantaged are criticized for their dependence (97-98).

Robert Murphy (1990) is similarly critical of what he refers to as 'the myth of independence', suggesting that '[l]ack of autonomy and unreciprocated dependence on others bring debasement of status in American culture and in many other cultures' (199, 202). In attempting to challenge the myth of independence, it is vital to recognise that able-bodied people are also dependent on many taken-for-granted "supports". Susan raised this subject in the following dialogue.

Susan: And people go on about how dependent you are and I read a fascinating thing … the example used is, you turn your tap on and water comes out of it. Why does it?
Because you depend on other people to make sure that water comes out of that tap. Now, the whole social dependency thing is important, but because you have a little bit more dependency compared to other people, you're labelled.

Arnold Beisser (1989), writes that the 'independence that I once prized I now realize was in part a luxury that I could indulge myself in because of self-deception' (41).

Our view of dependency is generally that it is a weakness and a flaw. There is a special pride one derives from feeling independent. It is a position that we have valued and taught. But I have come to a different understanding of the meaning of dependence and independence.

Every living being depends on others of its kind and the environment for nourishment and support. So a feeling of independence is not based on a belief that one is self-sufficient, but on a confidence that what one needs is available from the outside. The wider the circle that we can rely upon, the more we can feel and behave independently.

We confuse this feeling of independence with self-sufficiency, and interpret it to mean that we have done everything on our own. The belief that we are "self-made" men and women is a belief in a biological impossibility. That is the optical delusion of which Einstein spoke (43).

Many of the people who participated in this study, having recognised the myth of independence, have reconstructed the ways in which they view their need to interrelate in special ways with other people. One such reconceptualisation, as is suggested in the above quotations, is based on the recognition that we all rely on each other and on many taken-for-granted social structures for the fulfilment of our daily needs and that disabled people simply have different needs and are able to give in different ways. Adrienne talks about her own experiences as follows.

Adrienne: In America there is this fascination with pushing on and being independent and overcoming and all that kind of crap...[so] some of the things I'm really good at doing now really don't count for shit in a male world. Like, I'm a really good friend now.

Me: Yeah.

Adrienne: And that's still... that isn't high up on the list all the things that people put in your obituary.

Me: But, when you look at it, in reality...
Adrienne: It's really a gift ... And I know that the people whose lives I am in, part of that is that I am really important to them. I help them get through the day and they help me get through the day and we've got this kind of interdependence kind of thing going.

In a similar vein, Melissa Anne Goldstein (2000) writes that she came to understand that she could accept assistance from others without diminishment of self, because I could still help others, even if not as I had before ... I could still enjoy rich, full relationships that included giving and receiving on both sides. Possessing the knowledge that I could contribute to others was of paramount importance to me. I could still be the kind of person I respected. I could let go of the shame I had been carrying with me these past nine months. I also felt more secure; I no longer feared that people would abandon me.

Though this was a harder lesson for me to grasp, I learned how essential it was for others in my life to be able to help me. Their need to give was as deep as mine. They, too, felt powerless when confronted by my illness (124).

Another vital element in challenging normative values has been the redefinition of independence as the ability to make choices - or autonomy - rather than the ability to achieve things as a solitary individual (the 'polar explorer' as Adrienne calls it). Eli Clare (1999) puts it succinctly:

Independent living advocates measure independence not by how many tasks one can do without assistance, but by how much control a disabled person has over his/her life and by the quality of that life (89).

This recognition that independence necessitates autonomy is a vital ingredient in the redefinition of the disabled identity. For, if the challenge to the myth of independence rested solely on the argument that disabled people can still engage successfully in relations of reciprocity, then it is still possible that they may feel as though they are lacking. My proposition is that it is also essential to acknowledge that disabled people have the right to choose. As we heard Arnold Beisser (1989) comment, ‘a feeling of independence is not based on a belief that one is self-sufficient, but on a confidence that what one needs is available from the outside’ (43). Touching on the same issue, Lesley Tyzack (2001) writes that in her personal recovery:

As predicted in Erikson’s theory, my next need was for autonomy. If I was to succeed in becoming a person in my own right, I must make my own decisions, and accept responsibility for them. The medical profession and nursing home staff had taken over as “parents” and believed they knew what was best for me; some were encouraging, many were obstructive. An infant, if over-restrained or punished, may develop shame and doubt ... and in these circumstances, so did I. Could I be so sure my way was right? Did I “deserve” what I was demanding? Was I being fair to my caregiver? ... I was
fortunate that I had an adult brain that could reason and analyse because I was able to decide what was "my problem" and what was "their problem" and adjust my thinking accordingly. I considered myself successfully through this stage when I developed my will to the point where I could make my own decisions and insist on them in the face of opposition (2).

Making one's own decisions and remaining firm about them in the face of opposition is implicit in the need, or more appropriately, the right to decide what is best for oneself. Nancy, Chris Baker (2002) and Ruth Seinkiewitz Mercer (1989), all of who are reliant on full personal care, are very aware of how important their autonomy is to their independence. Each expresses this in relation to their need to maintain their independence of thought.

... it began in the fairly early days, I think I accepted the physical dependence, but my message was that, okay, I accept that you have to do everything for me physically. That's obvious. That's fine. And I accept that. But, when it comes to my mind or my spirit, keep off the grass. They are very much mine (Nancy).

There are paid to do a job. What's their job? It's being my hands and feet but not my head (Nancy).

But independence sure is a huge part of identity and that's the one thing that nobody can rob me of. It's just that it becomes more and more a cerebral thing, an attribute of attitude, and mine feels unshakable, stronger than ever, made that way by disability. Sure, I need help with damn near everything, but I sure as hell don't need help to think (Chris Baker, personal email: 11/12/02).

Despite my unavoidable dependency on others for physical assistance, I am a very independent person in thought and spirit (Ruth Seinkiewitz Mercer 1989: 12).

Managing to be autonomous when in need of so much assistance requires the ability to be explicit about things which people usually do for themselves without thinking about them. For example, Lesley Tyzack talks about the authority she had to develop to ensure that her assistants were doing things in the way she desired them to be done.

Lesley: You have to be explicit and give directions and, when they've done it, you have to check that they've done it. And people can get quite offended because you're checking up on them afterwards. But, you have to do it because they can forget or not understand what you've told them and do things wrong and that can have quite a bad... quite an effect on you ... You've got to be in charge and with me having my own money to pay people, they accept that. People that were paid by another agency didn't accept that I had any responsibility for it, not unless they had a reasonable amount of intelligence and realised that it was my life, but a lot of people weren't like that and thought that they were paid by the agency and would do what the agency told them.
Me: Whereas, now, you are actually in charge of choosing people?

Lesley: That's right. Yes, I actually advertise for them and I employ them and interview them and I train them and they know that they are here to do what I want them to do.

There are many elements that are mentioned by Lesley which impact on and/or facilitate one's autonomy. It has become essential for Lesley to become a highly effective human resource manager. She needs to be clear about what she needs and to feel that she deserves to be given the level of care that she requires. She has to be prepared to correct people when they get it wrong and to keep on trying to make her needs clear. She also touches on, not only the difference between paid and unpaid assistance, but also the different levels of autonomy accorded to recipients of these services. This would perhaps point to a difference between welfare related services and services which are purchased privately through the market place. Many of my participants talked about the negative attitudes which exists towards recipients of welfare services, an issue which will be dealt with in more detail in the following chapter on the effects that having employment, or not, has on one's identity.

Karen, who is dealing with the same individualised care funding system in New Zealand as that which Lesley refers to, argues that, even though she has to a large degree been able to be more autonomous because of this system, those in authority still do not fully accept her right to judge whether her care is effective or not.

Karen: They wanted to do assessments to see if the carers were doing their jobs right and they wanted to send somebody and come and watch me doing a shower and I said, excuse me, I'm not a piece of meat in the butcher's on display, I'm a person, and I said no. I said I'll tell you if my carers aren't doing their job right and they go, oh no, we've got our standards of what to do, and I said, sorry, but I'm not going to do it. One is, I'm not a piece of meat to be viewed. If my carers not doing their job right, I will tell you, and, two, we have enough strangers in our lives and my husband doesn't need to have another stranger come in to view me. And she says, I don't know what to do with you people. I said, what do you mean, you people. Are you going on about the fact that I'm not the only one who says no. She said, yes, I'm definitely going to have to get a dispensation for you people ... A lot of people in my situation don't think they have the right to say no, because they are scared they're going to have their care taken away from them if they said no. I said, by law, you can say no.

Me:. That's the threat, isn't it, because when you're depending on these people, whether they be doctors or carers or whatever, you feel like you have to please them or that you are indebted to them or...

Karen: That's right.

Me: But you've taken that power back again.
Karen: I've got [my power] all back again. It took a long time to get it back.

Me: I'll bet it did.

These statements indicate a form of personal power which goes beyond our current conceptions of “empowerment”. Empowerment, as Susan points out in the following statement still relies on the notion of being given certain allowable and specified areas of power, rather than taking this power as one’s own.

Susan: But, I don’t like the word empowered actually. It’s like someone else is letting you have the power, because they let you have it, and, you know, someone empowering you is giving you choices … That means they must have the power to give you choices … We’ll let you be independent. And that’s not independence.

I believe that the achievement of the kind of personal power which is being demonstrated by those who are succeeding in gaining independence built from autonomy is based on a different world view. To gain personal power when one cannot be self-reliant requires that certain myths be toppled and new rights established. From what can be seen in the stories told in this chapter, a properly independent life would not only allow disabled people to access a whole range of new possibilities for making comfortable and fulfilling lives for themselves, it also has the potential to resolve many of the attitudes which contribute to internalised oppression. People who do not feel they are morally inferior because they rely on others for certain forms of assistance and who can, moreover, access this assistance in ways which suit their needs and preferences are far better placed than those who live their lives in a state of guilt, embarrassment and deprivation.
Closely connected to the loss of independence were the losses related to people's identities as workers, particularly in relation to paid employment. No one used the term "paid employment". Most people simply used the term "work" to convey the concept of an income earning occupation. Some people were equally concerned about their inability to engage in productive enterprises other than those which attracted remuneration, but by far the most commonly lamented losses in relation to occupation were those connected with paid employment. Looking back to the genealogical investigation of disability outlined in Chapter Two, it is hardly surprising that not being able to work is looked upon as a severe loss. The industrial revolution not only created the necessity for a uniformly capable workforce which excluded those with impairments, it also removed people from their larger support groups and forced those who could not work for an income into a state of isolation and destitution. Indeed, it has been since this time, when the modern concept of the workforce came into being, that the term "disabled" has been used to describe those who, due to physical impairment, are unable to participate in paid employment.

The following quote from Robert Murphy (1990) demonstrates how tightly tied together is the current definition of disability with the ability to engage in the workforce.

When the 1980 census form arrived, I looked at the question that asked whether anybody in the household was fully disabled and checked "no." The question seemed to be one related to income rather than health, and I remained fully employed. My physical deficiencies would keep me from further research in the boondocks, but I was getting a bit old for that anyhow. Otherwise, I was neither "handicapped" nor "disabled" in my profession. And I took inordinate satisfaction in this (81).

In relation to those in my sample who were no longer able to work due to their impairments or disability, the extent of this loss varied according to the nature of the impairment(s), the type of work engaged in prior to the onset of disability, and how important it had been in defining the person's identity. Some people were able to gain or retain employment after becoming disabled and their statements of pride and satisfaction were as revealing as the statements of loss made by those who could no longer work. As was the case with the loss of independence - and of course they are intimately connected because of the "independence" that money can buy - people talked and wrote about the transition from being a worker to being unemployed.

Monique: I don't want to sound like I'm full of myself but like I had potential. I used to do performances and I'd have people come up and say oh wow that was beautiful. And I'd tell people I was a dancer and they'd say oh wow, it's amazing. And now it's like this question, I hate this question "what do you do?", you know, when you meet people. And
I used to get such an amazing response because I was a dancer, but now it's like I have CFS and I can't do anything and people go "ah" and it's really awful…

Me: That's why we end up feeling like that's what defines us because "you are what you do." This is what matters most in this society.

Monique: Each time it happens I feel smaller and smaller …

And naturally I'm fascinated by the impact of MS on things like identity. Of course the disease has an impact, and a very severe one for most people, especially those – and that's probably the majority – used to answering that rudest of questions, 'And what do you do?' with anything more comprehensive than 'fuck all.' (1) … Who am I, now that I'm no longer defined by occupation? (Chris Baker 2001: 8).

This then opened up a new set of problems, depression, irritability and most of all a feeling of failure. At the time of this I was a very successful and valuable member of the [Council's] survey department, in fact I was the highest paid and most experienced Instrument Hand in all of the [state's] local government authorities. Not being able to do the work I loved was devastating (Jack, written story: 1).

I felt useless and of little worth because I could not go back to the job I had had prior to my accident … As a fairly high functioning individual I felt like a total waste and I internalised the devalued attitude I continually encountered in others, in the media and even in myself. I often described myself as a 'parasite' because of inability to work and because I received ACC (accident compensation) …(Jacky, written story: 1).

Anne: Initially it was a nightmare and it was a very, very downward spiral for a long time, because I just felt useless, totally useless. From being in such a difficult job … I had to sit at home on the lounge while all this was happening …

Notice how these people are not referring to their loss of income, although this is surely a great loss in itself but more to abstract or emotional qualities such as pride and self worth. I, in fact, felt my greatest losses in areas which provided the least remuneration. My greatest pride had come from the creation and care of my organic vegetable garden. True, it was ostensibly a market garden and I sold produce each weekend at the local organic markets, but the returns per hour spent in the garden were so low that I often joked that I was performing a community service rather than making a living. Growing these vegetables fed my soul as well as my body and when I watched through the window as my garden withered and died, a large part of "me" seemed to follow suit.
Yet, it is also true that my income earning occupations contributed to similar areas of my identity. I worked in a variety of part time jobs at two orchards, a plant nursery and a tutoring firm. But, once again, the loss of income mattered less to me than my loss of meaning, fulfilment and identity. The horticultural jobs exercised my ability to nurture growing things and the tutoring, in an extremely comparable fashion, allowed me to help nurture growing minds. When I lost these activities I felt crippled in a way that went far beyond my physical incapacity and loss of income-earning ability. I felt crippled in the sense that I could no longer help to nurture potential and to encourage fresh growth. In the following excerpt Adrienne talks of similar feelings.

Adrienne: ... I don't think it was so much that my identity was threatened as it was the idea of not being the person that I used to be. I guess that is my identity being threatened after all. [She laughs]. The moment I admitted that, wait a minute, things were different, was when I stopped being an interpreter. I was in too much pain and I couldn't remember stuff and that was like this big, stone weight dropped around my neck. Oh why is this happening?

Me: You loved it so much.

Adrienne: I adored it. I absolutely adored it and it was like [Adrienne makes a mournful sound]. But at that point I went to a physician and said, this is really important to me, and she said, is that what you do for money? And I said, no, I have a job. [And she said], Oh well, guess it's not a problem then.

Despite the economic necessity for women to work, as well as the personal and social reasons, some people pointed to the gender-based differences which can result in men feeling more threatened by the loss of work as a primary mode of identification. Adrienne touches on this when she discusses the ways in which being a woman has allowed her to develop a more diverse range of self-defining features.

Adrienne: I think it's also the cultural expectation. Because the men I know with chronic fatigue are shattered by the idea that they're not being seen as capable wage earners.

Me: Yes.

Adrienne: So, I think that for once there is an upside to being a woman.

Robert Murphy (1990) comments that:

As could be expected, when women added wage-earning to their contributions as housekeepers and rearers of children, their status in the family increased markedly; in cases where the husband lost his job and the wife provided the sole support, role reversals have taken place. Despite all these profound changes in American society, an old
sentiment persists: A man who stays home is a loafer and a failure, but a woman who stays home is a homemaker. Women may work, but men must work. And since a large percentage of the motor-disabled are not employed, they are economic dependents, supported by Social Security disability insurance and the incomes of their families. As would be expected, this dependency affects the social standing of men more deeply than women (204).

Notwithstanding the fact that most of the women in the sample talked or wrote about the large impact that their employment status had on their identities, it was also the case that it was the men who were more likely to claim that their occupational status provided their primary mode of identification. Albert Robillard (1999), still able to work, writes with satisfaction that:

I have continued my career as a professor of sociology at the University of Hawaii. Except for my hospitalization, I have never missed a day of work (until, after October 1997, my wife was hospitalized and going to the university was out of the question for a short time). Work is my primary means of fulfilment (32).

Robert Murphy (1990) also describes how essential work has been to his identity.

... my own struggles against decline were made more intense by my attempt to deny my disability. My overreach beyond the limits of my body was a way of telling the academic world that I was still alive and doing what I always did. And all my feverish activities in both academia and my community were shouts to the world: "Hey, it's the same old me inside this body!" These were ways for protecting the identity, for preserving that inner sense of who one is that is the individual's anchor in a transient universe (82).

Kevin Hitchcock (1998) writes about the loss of his work identity and the consequent loss of self.

Apart from the innate power which goes with the position of Director of News, many people are apparently intimidated by my physical presence. That's reinforced by my reputation as something of a brawler, both on the football field and in settling drunken arguments. I'm not accustomed to having my decisions and instructions questioned. I am used to having the ultimate power in a workplace - the authority to hire and fire. Here I have no physical presence, no strong commanding voice, no mantle of authority. My suggestions and opinions are generally ignored. I feel I am just one of many. I am a nobody (183).

Once again it is evident that the primary qualities of concern to these men are less concrete than financial rewards. In describing what their jobs meant to them or what had been lost they used words such as "satisfaction", "identity", and "authority". These kinds of identity-based rewards can seem even more compelling when one has been denied mainstream employment for many years. Craig, for example, talks about finally getting a job after becoming blind at the
age of eighteen and spending years of frustration in sheltered workshops where ‘far from learning a viable trade, one ended up either making baskets, mats or wire coat hangers, or at the bottom of the pile, one counted jam jar lids into boxes’ (written story: 1).

Getting that job and moving back into the able bodied workforce and community changed everything for me. I still had problems, but self esteem and self respect went up and I began to get back to being "Normal". I made able bodied friends, bought my own little house, looked after myself for ten years, travelled to Australia, Fiji, Vanuatu, Bali, Hawaii, America and Mexico. Got involved with a Church group ------ All because I got a job with normal able bodied people, and could relate to them on the same level (ibid: 2).

Obviously the ability to be financially self-sufficient gave Craig more freedom of choice in his life, but he also felt that working for a wage built 'self esteem', 'self respect' and the capacity to live a 'normal' life. Karen also talks about the difference that this made in her own life.

Karen: Work has helped a lot.

Me: Yes.

Karen: Working in society, as we put it. And being part of the mainstream of life and just people seeing you differently. People do see you differently. People try to say, oh no, I don't see you any differently, but they do, and I know they do because I'm treated completely differently than I used to be. People would say, what do you do with yourself and when I used to say, on a benefit, you could see that its a lot different to now when I say I work for the department and they say, oh really, and that kind of attitude.

Me: It is a completely different attitude. Yeah, I'm experiencing that as well because I had to be on a benefit for a long time and now I'm getting paid a scholarship to do my PhD and I know that part of it, it's like you say, part of it is just me feeling better about myself, but it's true that other people are so much more impressed.

Karen: And what annoys me is that, why do we... how to I put it? I get annoyed with myself too because I like to shock people that way. Can I put it that way?

Me: Yes.

Karen: I like to shock people in that way because for a lot of years I couldn't. Now I can. It's quite an experiment sometimes, how people treat me. People that I haven't seen in years or something like that and they might come up and, say [Karen] I haven't seen you for a long time, what are you doing with yourself? Oh, I've been married 12 years and I've been working for five years and I've got my own home and I can see them treating me in a totally different way to the way they used treat me. I quite enjoy it. It's probably silly, but you get a kick out of it.
While it is not income that is cited as the main attraction to working, it is the loss or the possession of the income earning occupation which has the more critical effect on one’s identity. In my own case the combination of earning an income with doing the work I love has certainly contributed greatly to an improved self-image. Even though I had been studying part-time for seven years before I began my PhD, once I was being paid and my occupation sounded less like a hobby or a pastime, people began to react much more positively. And, although I am still trying desperately to care less about how others perceive me, I have been deeply warmed by the glow of acceptance that has been accorded me since I have been seen to be doing "real work" again. It's strange in a way, because before I became disabled I worked in relatively low paid, low status occupations and was not overly concerned with deriving my identity from my occupational status. But, now I gain an inordinate amount of pleasure from the respect my work attracts from others.

**Resisting the Loss of Employment**

Work proved to be such a necessary feature of people’s lives that many of the people in the sample talked or wrote about retaining their employment even when it was seriously detracting from their health and making their impairments much worse. Adrienne talks about this in the following dialogue:

> And in ‘91 I had to quit working. Between 88 and 91 I worked myself into the ground, which is unfortunately a common pattern for people with CFS … I didn’t stop when there were lots and lots and lots of things telling me to stop, stop, stop. And friends, my husband, and my good friend saying, you know, gee maybe this is time for you to begin to take it easier, quote, unquote. I mean it was really obvious, but I didn’t listen. I didn’t listen.

Adrienne was, as she refers to herself in a previous quote, ‘one of these ridiculously high performing people’ and it was very hard for her to stop working even when her body was close to the point of collapse. Even now, even after she has learned how vital it is to respect her body’s needs and limitations in relation to her case of chronic fatigue syndrome, she still feels lazy at times for not pushing harder.

> I’m so conditioned by the past decade of experiences not to push myself to do things... you know, because I felt like I pushed myself over the edge and that I was partly to blame for getting sick, because I was working sixty hours a week for one job and twenty hours a month for another job and going to community meetings and swimming and doing this and that and the other and I worked myself to death … but, when I need to beat up on myself I say, that's the perfect excuse for a lazy, slob like you. That’s my internal dialogue, but it's a very... yuck.
Chronic fatigue is a particularly problematic disabling condition as fatigue is poorly understood and those who develop it tend to feel guilty and confused about their diminishing ability to work. Rita talked about similar difficulties to Adrienne and a similar resistance to stopping until it became painfully obvious that the struggle to continue was extremely damaging.

Rita: I got a real guilt complex from not doing things and I'd try to do it and then I'd be wiped out again. Yeah, it was a drastic change. It took me a long time to accept the fact that I couldn't do what I used to do.

Me: It does take a long time to develop whole new ways of doing things.

Rita: Even when you try to force yourself to go on, it just gets worse. Because I tried to keep myself awake.

Me: That does make it worse.

Rita: I would force myself to do things and I got so achey and tired that I'd just go into tears and that sort of counteracted everything I was doing.

Anne also talked about her resistance to giving up work after she injured herself. She kept pushing herself until, ultimately, she was so disabled she was barely capable of getting out of bed.

Anne: With teaching disabled kids, or the kids that I taught, it was much more painful for me to do... there's a lot of lifting with teaching anyway and with those kids, they quite often have emotional outbursts and you have to hold and rock them or whatever...

Me: So, it's much more physical job...

Anne: .... much more physical than normal teaching. Yes. And sometimes I had to lift kids, for whatever reason. Anyway I found it really painful, but I kept going ... I'll just tell you. I'm from a Yugoslav background and we have the stoic work ethic thing that you never stop and, you know, you just continue to work. That real Slavic thing of never ever stopping and, for me, I've had to approach ... culturally too, it's been quite a difficult thing for me. For me to accept that, you know, there is a limit [laughs]. You can't push the body too far.

Robert, also kept working through a severe back injury, the loss of a finger and his current chemotherapy treatments, was proud to say that he was still noted for working harder than most people do under normal circumstances.

Robert: As a comment was made to me, your light duties, what you consider as light duties, a lot of people are flat out doing it as normal work.
Me: Right, and this is when you were going through, what, the recent kind of stuff, like when you were doing your chemotherapy?

Robert: That was my back.

Me: My goodness, and you had surgery ... yeah?

Robert: Yeah.

Me: So, you were still working when your back was in so much pain...you described it very vividly the other day.

Robert: Yeah, yeah, I was still working when it was like that.

Like Robert, I have recognised for some time that I now work far harder than I ever worked before I became disabled. Robert Murphy (1990) also talks about his resistance to stop working despite the seriousness of his illness.

During the winter of 1980-81, my general state of health began to decline markedly. I developed colitis, in part a byproduct of overwork, and a series of bladder infections. These combined with the infected ulcer to produce frequent low-grade fevers and left me vulnerable to a rather bad bout with flu in February. But I kept on working, driven now by an almost manic need for self-assertion and continuity. I was no longer so much denying the illness as defying it. Yolanda finally took matters into her own hands and told my doctor about the problem. He took one look and said, “Good God!” (180).

Hugh Gallagher (1998) also kept working until his ultimate collapse.

I continued in this desperate fashion, wracked with constipation and insomnia, until July 4, 1974. On that day, I bombed out of Super Cripdom. My body collapsed physically, and I plunged headlong into a deep and chronic clinical depression, which took me years to climb out of (Hugh Gallagher 1998: 246).

At the time of the following dialogue Angus was still working although his health was making this extremely difficult. His illness had almost forced him to give up working two years before and, when asked how this made him feel, he replied:

Angus: It was just an abyss, like a black hole that I just couldn't imagine, and I was thinking things, without being suicidal. Right, I don't think I've ever truly contemplated... I mean, I've thought about suicide in an intellectual sort of way. I can even tell you how I would do it if I had to. It's simply with hypoxia. It's a very nice way to go but, not for a
moment do I plan to top myself. However, I can remember thinking, well, a good option would be to sort of die, without planning to make this happen at all, but just thinking that dying would solve all of those problems.

Me: Because life was unthinkable.

Angus: That's right.

The insights so far provide overwhelming evidence that those who could no longer work felt diminished and were unable to maintain their former senses of self, while those who could work highlighted its importance in relation to creating or maintaining a positive identity. These feelings of pride and diminishment are directly related to an overarching social view that to be a good person, a good citizen, one must be active and productive and financially independent. When this is no longer possible, in each of the countries from which participants were drawn - Australia, New Zealand, America and the United Kingdom - there are welfare systems in place to help support those who cannot support themselves because of disability. Yet, the view towards those who rely on this kind of support is uniformly negative.

**The Values Surrounding Work and Welfare Dependency**

Those people who needed to rely on social welfare talked about its moral implications and the feelings of worthlessness that being dependent on the state brought with it. Michael, a recipient of what he refers to as "disability" in the United States, expressed it very eloquently in the following dialogue.

Michael: Here we call it a welfare mentality. And this is really organic to our culture, the free enterprise, hardy, individualist culture and, you know, I suppose this goes back to workhouses, you know, Charles Dickens, that the only honourable way to proceed in life is self-support. And, therefore, if you rely on the state for support, you are morally reprehensible.

Me: Yes. It's still there, isn't it?

Michael: Yes it is, and that's the whole thing about [the attitude of social security bureaucrats], "I can feel free to be demeaning to you and to know that there is no standard of service whatsoever regarding the way I treat you and the mentality behind that is that you are essentially a beggar and anything you get, you should feel lucky that we don't just put you out on an ice flow and let the polar bears get you."

During our many dialogues, Michael, who practiced law before developing chronic fatigue and fibromyalgia, stressed the demoralisation and the bureaucratic nightmare that being in need of
welfare support brought to his life. Craig, who is reliant on the non-means tested Blind Pension in New Zealand, also expresses how this makes him feel.

Craig: We are disabled, we are in a disadvantaged position, on the benefit through no fault of our own, and thank God for it, but the moment they threaten to pull it on us, or do anything to it... they've cancelled it on me a couple of times And, unfortunately it's like that with so many things for the disabled. We go in, cap in hand, almost with the begging attitude because society has conditioned us to do so and, because in so many cases, there is no other way. I mean, let's face it, if it comes to a job, they're not going to come to me.

During this conversation, Craig told me that the reason his benefit had been cancelled was that they had questioned how blind he actually was, whereupon he pointed out that he has had both eyes removed. We discussed how difficult it is to deal with these kinds of attitudes, the kind that are imposed on us when we have to deal with the welfare system, and Craig develops an interesting argument in which he suggests that we have what he calls a "headmaster complex" that affects us every time we are in a situation where we have less power like a doctor surgery, social security or the boss's office.

Susan, who lives in the United Kingdom and talks extensively about how much more important work and a career are to her now than they were before she became disabled, expresses what she believes is the general view of the population.

Why should the country keep helping you, keep giving you benefits. I pay my taxes to help you stay at home and do nothing. Okay. Fine. And that's the way that people see it, isn't it?

During a dialogue with Terry, an Australian man now living in New Zealand, we talked about the losses that come from not being able to work anymore. He points to how work 'really builds your self esteem', 'gives you financial independence' and 'broadens you social network'. He talks in detail about these losses throughout the dialogue, but what seems to hurt the most is that disability 'makes you totally dependent on the state and that's a really terrible thing.' Jacky, already quoted for her feelings of loss, writes that:

I felt like a total waste and I internalised the devalued attitude I continually encountered in others, in the media and even in myself. I often described myself as a 'parasite' because of inability to work and because I received ACC (accident compensation) …(Jacky, written story: 1).

Recall also that, when Karen was speaking proudly of her job and the difference it had made to how other's viewed her, she referred to her previous status as a recipient of welfare benefits.
People do see you differently. People try to say, oh no, I don't see you any differently, but they do, and I know they do because I'm treated completely differently than I used to be. People would say, what do you do with yourself and when I used to say, on a benefit, you could see that its a lot different to now when I say I work for the department and they say, oh really, and that kind of attitude.

All these reflections and comments illustrate the attitudes that recipients of welfare benefits are exposed to, attitudes that cannot help but be internalised. My own experience with being forced into the welfare system was similarly damaging to my self-perceptions. Six months after I hurt my back, the system of benefits in Australia was restructured and it was decided that people who had been on sickness benefits for more than three months would have to move either to the invalid pension (now the disability support pension) or unemployment benefits. I was automatically placed on unemployment benefits and was required to fill in a fortnightly review form which contained a question concerning my ability to apply for work during that period. Despite the enormous pressure that was applied on me to do so, I would not tick the box which declared me fit for work because my pain and immobility were so severe that work of any kind was out of the question. Six months later, due to my recalcitrance and the reality that my impairment would not go away, I was finally allowed to apply for the invalid pension.

At that time there was a shift in government policy which led them to target this benefit as an area where extreme cuts would be made, aiming to halve the 400 000 people in receipt of the benefit during the following twelve month period. Therefore, it was not a good time to be applying and the Commonwealth Medical Officers (CMOs) who were responsible for assessing one's eligibility for the pension were told to be very rigorous in weeding out malingerers. During my interview and examination by a CMO I was treated with such emotional and physical cruelty that I felt crushed by it. No matter how upset I've been I have not allowed myself to cry in a doctor's surgery before or since. But that day I could not stem the flow of tears. And the feelings which accompanied those tears of humiliation and distress became deeply woven into the demoralised identity I came to take on due to my disability.

Part of this kind of harshness appears to derive from the view that disabled people should be able to triumph over their adversity. Hence, if recovery or rehabilitation do not progress as planned, then the disabled person is claimed to be a malingerer. Melissa Anne Goldstein (2000) writes about the harsh judgments that she received from doctors before, and even after, the seriousness of her condition was understood.

"You're not in school. You're not working. What do you do with yourself all day. Stay in bed?" With these words, Dr. Hornbach, a doctor I barely knew, addressed me, his tone accusing as he entered the room and planted himself in front of me. I lay on the hard gurney shocked into muteness. I stared up at Dr. Hornbach. He had a broad build with the solidity of granite, an immovable object cloaked in white. From his height of over six
feet, he looked down at me, his craggy face and ice-chip blue eyes showing no compassion. His eyes clearly did not see me the way I and others thought of me - as a twenty-seven-year-old writer, a poet, and a young woman who despite the ravages of disease had retained her identity, dignity, and femininity (5).

On another occasion a female doctor expressed similar sentiments.

I then tried to make her understand my frustrations about not being able to work over the summer and my worries about not having enough energy and strength to keep up a busy schedule in the fall. She was my physician. I thought that meant I could confide in her. There was an empty pause before she answered. Then she coldly informed me that my inactivity resulted from excessive anxiety, not disease, and that there was no reason to be concerned about returning to school. She suggested counseling to help me deal with my anxieties. Either I could find someone on my own, or she could recommend the behavior modification unit at the university hospital. I was stunned. Before I could respond, I heard the click of the receiver, then the dial tone. She had hung up. And left me alone on the other end of the line (82).

I have experienced similar disdain from the medical profession. One instance which is relevant here is drawn from recent correspondence.

During the early years when I was still seeking a cure for my back, I had waited two months for an appointment with one of the Gods of orthopaedics at Royal North Shore Hospital. I remember the journey down to Sydney from Katoomba [lying in the back seat of the car]. It was two hours of hell as my back screamed out at the slightest bump or application of the brakes. Then there was the terror and agony of having to negotiate unknown territory when I could barely walk. When I finally got settled in the surgery I didn't even get to see the great god himself. He sent me an underling, a really young and arrogant doctor who said "I can see what your problem is. You need a job." All my hopes were dashed in a couple of short sentences. He didn't have a clue (personal email correspondence, 13/3/03).

This doctor simply assumed that one must normalise to the greatest degree possible, and that, after a certain time has passed and a physical cure cannot be exacted, one must achieve these ends regardless of the level of physical incapacity. Perhaps I would now be able to answer him by asking which profession he thought would be suitable for someone who was bedridden and in agony, but, at the time, my only response was the silence which overlay my feelings of disappointment, alienation and minimization. As Arnold Beisser (1989) and Robert Murphy (1990) agree, rehabilitation is seen to be a form of work itself, one which, if it does not achieve the desired results, is believed to be a case of personal failure. Arnold Beisser (1989) writes:

As far as working "hard enough," I do not believe that anyone could have worked harder at his rehabilitation. In fact, that effort became a detriment in several ways. Patients were
told that the degree of improvement would be equal to how hard we tried. We did not
know then that beyond a certain point exhaustion produced even further damage. We
were told that the enemy was the contracture that developed in the weakened muscles,
and that we must endure pain in being stretched. I was so willing to endure my share,
that I have several muscle groups that have been seriously overstretched.

So firm was belief in hard work among the people I encountered in rehabilitation
medicine that nothing would dissuade them. If you were not improving the way
you hoped, it was simply, in their view, that "you didn't want it enough." Perhaps they
were not so rigid as I remember, but rather it was the stricture of my beliefs at the time
that I was dealing with.

If I were to give up my cherished conviction in being able to make things better, I would
have a void in my belief system, and I did not have anything to replace it. I did not have
some way of regarding my life which would allow me to live with it. Surrender seemed a
matter of cowardice, and I did not want any of that.

Only as the years wore on and forced me to realize that my limitations remained
unchanged did I begin to consider alternatives. I felt as though I were dragged, kicking
and screaming, toward this new version of reality (118-119).

In a similar vein, Robert Murphy (1990) draws the following conclusions from his own
experiences.

Rehabilitation differs from other branches of medicine in the degree to which the patient
is involved in his own treatment. Ideally, he is active, not passive, and he must try
continually to outdo himself. To a degree, the patient is responsible for his own recovery,
and this has many positive aspects. The negative side of patient responsibility, however,
is that if his efforts cannot yield improvement, then any failure to improve can be an
indication that he isn't trying hard enough, that he is to blame for his own condition. This
load of culpability is often added to a lingering suspicion among family and friends that
the patient was responsible, somehow or other, for what happened to him. And the
patient, too, is often beset with guilt over his plight - a seemingly illogical, but very
common, by-product of disability. In this way the patient's inner circle can escape a
sense of remorse over his travails, and the medical establishment can absolve itself of
responsibility for the failure of its procedures (52).

Craig refers to another form of pressure, closely connected with the rehabilitation mentality,
which is based on the belief that, if one person with a particular type of disability can perform
certain tasks, then they all should be able to.

We have here in New Zealand a Blind gentleman, that has been seen on TV using a
chain saw to top a tree. The question immediately is asked, "Can you do that?" The next
question is "why can't you do that?" The next statement is "You ought to be able to do
that." Next "You must do that", and when you say "I can't do that," they hit back with "Can't means won't, you are a welfare bludger, who just doesn't want to work." Now, from a Blind perspective, that chain sawing gentleman may be able to use his saw to top a tree, and if he feels comfortable doing such things, that's fine, but don't let anyone think that he represents the rest of the Blind community. The vast majority couldn't do what he does. Most wouldn't be silly enough to attempt it (written story: 17).

In this example of the pressure to act like "normal" able-bodied people, Craig points to the expectations which are created when some people engage in feats which highlight the possibility for triumphing over disability. And, indeed, some disabled people maintain flourishing careers (cf. Gallagher 1998, Robillard 1999, Murphy 1990), others learn to fly aeroplanes (cf. Shepherd 1994, Arnot 1998) and still others climb Mount Everest (cf. Whittaker 2001, Team Everest 2003). While these are very worthy achievements, their utilisation as mechanisms to inspire other disabled people can leave those who are not capable of anything like these feats feeling very inadequate. When this kind of pressure is applied in concert with the rehabilitation ethos to suggest that all people are capable of doing some kind of work, and that those who do not work are somehow lesser individuals, the pressure to perform is enormous.

Challenging the Imperative to Work

Unlike the category of independence/dependence where many people talked or wrote about the development of new perspectives to combat the oppressive views which can exacerbate the feelings of loss associated with disability, the subject of work attracted little talk of resistance. It appears to me that this is the case because the expectation that we all should work to earn a living and to define who we are is so ingrained that any suggestion that it is possible to develop a meaningful and pleasurable life outside of it becomes unthinkable. Even the disability rights movement which has challenged the individualistic attitudes which currently frame our views of independence bases its aims on the right and the necessity for all disabled people to be able to gain employment and, thus, does not focus on challenging the imperative to employment. There is no doubt that this is part of the answer because discrimination in the workplace is a serious issue and there are many people who would be able to engage in productive activities if these barriers were removed. However, what may be overlooked here is that many people may not in fact be able to undertake regular work and the continual pressure that is put on them to do so reinforces their feelings of inadequacy. Hence, I believe that, for this and other reasons, a new way of viewing productivity and social worth needs to be developed outside of work.

Four people from the sample spoke of developing new philosophies around the issue of work and social value. The first of these, Adrienne, has not been able to return to paid employment because of the severe and unpredictable nature of her condition. So, she now spends as much time and energy as she can working for change in relation to disability rights issues.
I'm not working yet, but my business cards says civic activist. I'm involved in various [unclear] disability organising around transportation issues.

In doing this, Adrienne looked for things she could do which would help her 'to build a life that is gratifying like the one I left behind.' To make up for the losses she experienced when she could no longer be an interpreter, she volunteered at the local English language speaking centre and became a 'conversation buddy to people who were learning English.' In the following dialogue she discusses the new perspective about work and productivity that these activities and the accompanying insights have inspired.

Adrienne: ... there's a certain kind of stereotype of an upper middle-class woman forty years ago... it was like they would never work for money, but they would be like... not quite like the charitable women...

Me: More active in the community. Yeah.

Adrienne: More active in the community. They helped to ensure that there was tutoring in the schools and the arts were supported. I mean, there was a whole range of roles that they fulfilled, and nobody would say... I mean people would say, what are your interests? Not, what do you do? What are your interests?

Me: Mmm.

Adrienne: It's so much more a kind of... you know, it's a thing that you defined and not something you are measuring up against. So, I tried to think, well, that's my heritage, this bizarre kind of middle-class "ladies for lunch" and sometimes when people say, what do you do, I say, I'm a lady of leisure. [She laughs and I join in]. And I just play with it.

Me: Yeah, play with it. That's great.

Adrienne: But I recognise... it didn't take me long to realise that I can do the volunteering, the things I like to do, and, when I'm volunteering, I can decide how much to do.

Me: You can define the boundaries.

Adrienne: Exactly.

Dianna also points to the tremendous significance of activities outside the workforce.

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8 See http://www.teameverest03.org/
I used to feel there was a distinction between those people who knew me before I had MS and those friends I have made since. I used to think that the ‘befores’ treated me differently than the ‘afters’; that they see more of the person and less of the disability. But I am rethinking that one. Because I am very active in the local world of politics, disability, Labour Party, book group, pub quiz among some of the things I do, I think people see me for what I can do rather than seeing the wheelchair. And there are so many things nowadays where the wheelchair is a positive advantage because they are wanting to hear an opinion from a consumers point of view. A transport group that I am on, I Chair because they want a user’s voice to be out front. So my identity is enhanced and a positive asset. What a change from 30 years ago (1).

Arnold Beisser (1989) wrote about a deeply philosophical change which challenged his previous belief in the necessity for working and pushing forward and replaced it with the ability to accept what life offered. I place it in this section because it speaks eloquently of a new way of seeing things which is outside of the dominant paradigm which governs the imperative to work.

When I was growing up, I learned that I must “make something of myself” and make a place in the world. Making the necessary changes to become something and to find a place were acts of will and effort. I learned that those things were possible if I was willing to work, to plan, to expend effort, and to struggle.

The implications were clear. I was “not enough” to begin with, and there was not a place for me in the world without my making it. Order had to be created. I had to change myself through discipline and effort. The world had to be changed to make it a better place to live in. Self improvement was required, and the world had to be civilized. Willful, enforced change was the only kind that I learned.

My disability has taught me that there is also another kind of change. I reluctantly learned about it through defeat. I faced something that no amount of work, effort, planning, or struggle could give me. Defeated on all fronts, I had to learn how to surrender and accept what I had become, what I did not want to be.

Learning to surrender and accept what I had not chosen gave me knowledge of a new kind of change and a new kind of experience which I had not anticipated. It was a paradoxical change.

When I stopped struggling, working to change, and found means of accepting what I had already become, I discovered that that changed me. Rather than feeling disabled and inadequate as I anticipated I would, I felt whole again. I experienced a sense of well-being and a fullness which I had not known before. I felt at one not only with myself but with the universe (Arnold Beisser 1989: 168-170).

Paul Hunt (1966), who edited and contributed to the anthology *Stigma: The Experience of Disability*, wrote about a similar insight into the ability to accept things rather than overcome
them, but he more clearly expressed this in terms of work. He, of all those whose writings are represented in the sample, was the most courageous in challenging the imperative to work.

I am concerned that we should not telephone the idea of work in our minds to the point where it dominates values that ought to transcend it. It is important not to do this, if only because it causes the most acute suffering in those of us who cannot help being parasites on the economic body.

Obviously we who are disabled are deeply affected by the assumptions of our uselessness that surround us. But it is vital that we should not accept this devaluation of ourselves, yearning only to be able to earn our livings and thus prove our worth. We do not have to prove anything.

If we have a basic willingness to contribute to the community, yet cannot do an ordinary job, we may certainly contribute in less obvious ways; even, and perhaps especially, if these seem insignificant beside the ‘real world of work’. Our freedom from the competitive trappings that accompany work in our society may give us the opportunity to demonstrate its essential elements. Also we can act as a symbol for the pre-eminent claims of non-utilitarian values, a visible challenge to anyone who treats his job as a final end itself. And we do of course afford people the chance to be generous in support of the needy, thus enabling them to give practical expression to their desire to go beyond the acquisitive instinct.

At the ultimate point we may only be able to suffer, to be passive through complete physical inability. Just here we have a special insight to offer, because our position gives us an extra experience of life in the passive aspect that is one half of the human reality. Those who lead active lives are perhaps especially inclined to ignore man's need to accept passivity in relation to so many forces beyond his control. They may need reminding sometimes of our finiteness, our feminine side in the hands of fate or providence. We are well placed to do this job at least (149-150).

Hunt’s philosophy of acceptance is very similar in nature to the one described by Chris Baker (2002). Both emphasise that we cannot be in control of every facet of our lives and that there are circumstances over which we have very little control at all. Acceptance, then, lies behind the capacity to develop a positive identity despite, and because of, disabling circumstances. Yet, our cultural beliefs tell us otherwise. The belief that we can control things and that hard work will win through every time is fundamental to contemporary Western values and is deeply woven into the rehabilitation mentality. When we base our response to disability on these premises, we feel that recovery and a satisfying life are achievable if only we try hard enough and that, conversely, if we cannot succeed, we are at fault.

Challenging this does not necessitate a loss of motivation. Motivation and acceptance are not mutually exclusive, yet our dominant paradigm constructs them as dichotomous. A new
perspective is required to challenge the imperative to paid employment. What needs to be accepted is that, if it is not possible for a person to engage in what we currently construe as work, either because of physical limitations or economic conditions, then it should be possible for them to achieve happiness and a positive identity outside of it. To make this achievable, the view of paid employment as an essential ingredient in a worthwhile life needs to be challenged and changed. It is certainly the case that disabled people usually enjoy far less flexibility and choice in their lives due to their impairments and their social exclusion. Yet, not being a part of the traditional workforce could actually be reconstructed as a positive quality, offering more flexibility to those who can begin, like Adrienne, Dianna, Arnold and Paul, to find new and diverse ways of developing productive lives.

This way of thinking brings to mind a conversation I had with one of my participants. We were talking about the losses that disability can bring and how one comes to terms with them. Lesley then turned the conversation to the advantages that can stem from the new life one must build to accommodate one’s impairments.

Lesley: Yes, though there was one thing that worked to my advantage. You see, it was always my secret dream to live on my own in a flat with no other people to consider...

Me: Ahhhhh.

Lesley: ... surrounded by books and I had lots of books, so I had what was probably my starting point.

Me: Because you were given an opportunity that you would never have otherwise been given.

Lesley: That's right.

Me: And I think that happens a lot, don't you? ... Because, even though originally it's like, oh no, everything’s been taken away, and there's nothing left and it's horrible, you also find all sorts of freedoms that you never dreamed existed within that.

Lesley: Well, this was one that had already been my secret dream [she really does say this with absolute relish] that one day I would live on my own surrounded by books and just live the sort of life... did you watch Inspector Morse?

Me : Oh yes.

Lesley: You know, his sort of lifestyle... to read good books and have a nice glass of wine...?

Me : Lovely.
Lesley: That was my dream. And, I unexpectedly got loaded with that.

Me: That is amazing, isn't it?

Lesley: Yes, because there are... well, there are different dreams, but that was a dream you already had [and becoming disabled] allowed that to be able to happen. So, that was one positive that came out of it and that, I think, was my starting point.

The life that Lesley led prior to developing MS was one which was framed by the social expectations of the time. As well as being a wife and a mother, she held a demanding job and her time was very much mapped out and limited by these responsibilities. Her dream for some space of her own and the time to read and pursue her own interests unexpectedly became possible some years after her disability became extreme. I believe that this can be perceived not only as a compensating factor, but as an example of the kinds of subversions which living outside of the constraints of the norm can offer. Those who become disabled will usually suffer a great deal of distress because of not being able to fulfill the expectations of the norm, yet they can also, over time, come to see alternatives to the norm which can allow all kinds of freedoms never before imagined or, as in Lesley's case, imagined but not attainable.

Lesley, as you may recall from Chapter Six, became so severely disabled that she was given permission and the means with which to end her life. Following her recognition that her will to live was too strong, she reached a turning point in her life which allowed her to move forward. It is the discovery discussed above which she says became her 'starting point.' She now describes her life as follows.

Since I wrote [my essay on identity and disability] in 1998 I have continued studying part-time and expect to graduate with a BA in two years time, majoring in psychology and political science. I live alone in a small flat with a voice-activated computer and environmental control units that make me completely independent. I receive funding that allows me to employ helpers who come in four times a day to help me with showering, dressing, meals, and anything else I cannot manage alone. I am the vice president of the Christchurch branch of the Disabled People's Assembly, I belong to Toastmasters, which is a public speaking club, I play chess weekly, and I have five grandchildren between the ages of newborn and five years, four of whom live in Christchurch, and one in Tasmania. At present I live on a social welfare benefit, but I have recently started working at two direct marketing businesses that are disability friendly and promise to be very profitable. Nowadays I would describe myself as, happy, cheerful, contented, comfortable, loved, popular, motivated, busy, stress-free, optimistic, interested, interesting, intelligent, and well-informed. Perhaps it is going too far to say MS was the best thing that could happen to me, but it was certainly the making of me (personal email correspondence, 16/11/01).
I believe that the reconceptualisations and meaning making activities that Lesley refers to above were made possible, at least in part, by the development of a new way of seeing what constitutes meaningful activity and how this affects identity. Certainly Lesley's story can be seen as one of incredible triumph and can be construed as inspirational. What I believe provides the most effective inspiration, however, the kind of inspiration which will not leave those who cannot scale similar mountains feeling inadequate, is that which stems from the way that Lesley has been able to define a whole new way of making meaning and building her identity which lies outside of and challenges the norms which once defined her life and her possibilities.

In my own case, I find myself suspended between two mutually contradictory spaces. The first one is that which is defined by my new compulsion to engage in socially sanctioned work. As I have already discussed, prior to becoming disabled, my primary form of identification was connected to my occupation as a grower of organic vegetables. This was linked with my stained glass and pottery projects and my aim for self-sufficiency and environmental harmony. The combination of these activities helped to define me as someone who was creative and who was pursuing an alternative lifestyle. Part of this pursuit was related to challenging the importance of high paid, high status employment. Yet, when I lost the luxury of choice in this regard and suffered from the severe identity losses which follow the onset of disability, gaining employment and social approval became far more important to me. This is only evident to me in retrospect in light of the boost that earning an income for a well respected occupation has given to my feelings of self worth.

On the other hand, however, I have also come to delight in some of the very subversive elements which structure the occupation-based space I now inhabit. Working from home allows me to choose how to organise my time in a way that best suits me. Some of what "suits" me is unfortunately connected to a very unpredictable state of health which means that I am sometimes unable to work at all. But, in addition to my physical limitations, my needs and desires can also be facilitated within an environment that gives me a great deal of choice as to how and when I engage in my work. Disability has also led me to a type of work that is creative in a different yet similar way to my past work of growing things, making things and helping people to learn. I now grow ideas, build new ways of seeing things and hope to educate through my writing. And I have discovered a kind of work which allows me to explore and challenge the social issues which have always interested me most, those which are focused on social exclusion. This work is enormously satisfying at the same time as being productive and flexible. Like Lesley, I surprised myself by carving out a dream existence from the core of a nightmare.

Many other people within the sample reported that they had discovered various "gifts" in relation to becoming disabled when they began to challenge the forms of oppression which contribute to the disabled identity and to realise that this allows for the possibility of creating a new more liberated space in which to live. To learn to speak out to break the silence, to define
independence in new ways which create more warmth and freedom and choice, and to learn to structure a fulfilling existence outside of the imperative to work are all tools which can be used to carve out this emancipatory space. To work, to be productive, to contribute to society are obviously very vital features of a worthwhile life. Yet, the narrow view which currently exists towards occupational identity and the need for self reliance has resulted, as it has been shown in this chapter, in the creation of a very inferior social location for those whose physical limitations exclude them from participating in socially sanctioned ways.
CHAPTER EIGHT

Looks Can Be Deceiving: Appearance, Sexuality and Shame

How do others decide whether a person is "disabled" or not and, as a consequence, set in motion the processes of value judgment and exclusion which truly disable people? Those who have what are commonly referred to as "invisible disabilities" may choose to pass as able-bodied. Only when less conspicuous issues such as not being able to work or needing help from others come to the forefront does the impaired person face the imposition of disabling judgments. Yet, for those whose impairments are clearly visible, the allocation of a disabled identity can occur before they are given the opportunity to reveal any other distinguishing characteristics. Accordingly, appearance is often the front-line indicator of a disabled person's physical difference and is all too often the focal point from which negative attitudes are generated.

The visible physical differences which were perceived as problematic by those in the sample were extremely diverse. Some were related to changes in size and shape, such as when people gained or lost significant amounts of weight, when muscle tone was lost, or when the shape of a particular body part was altered in a socially unacceptable manner as in "deformity" or "disfigurement". Other visible differences were involved with changes in observable movement and position in space: such as the involuntary movements associated with epilepsy, cerebral palsy, familial tremens, spasmodic torticollis, Parkinson's Disease and Turettes Syndrome; the lack of movement which stems from spinal chord injuries or other immobilising conditions; the changes in body language associated with movement disorders and sensory disabilities; and the solidification of spatial orientation which comes from being fixed in a sitting or lying position.

Also conspicuous were the aids that help to compensate for certain features of some impairments such as wheelchairs, leg braces, back braces and catheters.

Obviously, some of these visible signs of disability tend to attract more negative attitudes and disempowering self-perceptions than others. For example, it is evident that Lucy Grealy's (1994) and Caroline Shuck's (2000) facial disfigurements and Albert Robillard's (1999) drooling and the constant presence of the urinal have a more dramatic impact on identity than moderate weight change or the use of a cane. Yet, what all these physical manifestations have in common is that they can function as what Albert Robillard (1999) refers to as 'stigmata', signs of physical difference which incite aversion, exclusion and sometimes even punishment. These signs, on their own, are meaningless. They only become stigmata when they are invested with social meaning according to the rules of normality that they violate.
The Stranger in the Mirror

People's initial response to their changed appearance was very often a lack of recognition. As with the loss of identity associated with work and independence, changes in appearance created a sense of dissonance between past and present identities. Nancy was bedridden for many months before she was able to reach the point where she could sit in a wheelchair. She remembers this day very clearly and says 'the first day up in the wheelchair, quite honestly, Rose, when they put me in front of a mirror, I didn't know it was me'. Jane also touches on this lack of recognition in her written story and connects it with her overall feeling of involuntary transformation.

Jane: I keep wondering every time I look in the mirror who the hell this fat woman staring back at me is. I must be lazy and unmotivated to have let my appearance slip so bad, right? … Did you ever see that movie "Big" with Tom Hanks? Kinda like that - going to sleep a kid and waking up 10 years later and wondering why the world's different.

The first time that Joni Earickson (1976) saw herself in the mirror after her accident she was so deeply shocked that she began to feel suicidal.

The figure in the mirror seemed scarcely human. As I stared at my own reflection, I saw two eyes, darkened and sunk into the sockets, bloodshot and glassy. My weight had dropped from 125 to 80, so that I appeared to be little more than a skeleton covered by yellow, jaundiced skin. My shaved head only accentuated my grotesque skeletal appearance. As I talked, I saw my teeth, black from the effects of medication.

I, too, felt like vomiting.

Jackie took away the mirror and began to cry with me. "I'm sorry, Joni," she sobbed, "I didn't want you to see."

'Please take it away. I never want to look in a mirror again!' (38).

Kevin Hitchcock (1998) also expresses horror at the sight of his image.

It's the first time I've seen myself almost fully naked since the accident six weeks ago. The face is familiar, but it's supported by the body of a seventy-year-old man. Gone are the broad, square shoulders and solid, tight muscular frame. I'm looking at sagging shoulders, sunken chest, thin bony arms … and ribs! The short, army-style haircut, courtesy of Marg, doesn't help. I look like a survivor of a concentration camp. It's frightening to think I have lost so much in such a short time. I don't know how much weight I've lost, but I'm shocked and desperate to find out. There's something else. My body hair has changed colour. Staring down, I discover my legs are covered in brown, almost black, strands, not blond. On further investigation, I realise my chest and
arms are the same. What does all this mean? It's something else I have to find out from the experts (155).

When Samantha wrote her story in response to my request for a sharing of the factors related to identity and disability, she began with appearance.

Samantha: Let's start with body image. I used to be quite slim but now I look like a female version of the Michelin man! I can joke about it when it's just an abstract concept, but the truth of it frightens me. Aside from health concerns that obesity raises, I feel so alien in my own skin … Other times, I can still see the person I was staring back at me, and I know that it's not my fault. But thinking of the fat stereotypes - lazy, greedy, unmotivated, slobby, and all the rest - does nothing to inspire me to do what I can to change my body.

Like Samantha, although in different ways, my body image changed dramatically and I found it hard to come to terms with the person in the mirror. The intense pain of my back injury drained me of colour, gave my eyes a sunken, haunted look and changed my movements from smooth and easy to slow, stilted and self-conscious. My long, thick hair dried out and broke and then, after I contracted glandular fever, much if it fell out and I felt like a scarecrow. The firm muscles built from strenuous work withered and atrophied, my skin paled and sagged, and I quickly began to look much older. On a "well-ish" day, accompanied by relatively low pain levels, I can look ten years younger than I've become accustomed to looking. But on the bad days, which are most days, I think I look old and frail and withered, drained of life and dried out like a prune. To add insult to injury, my genetic legacies of familial tremens and spasmodic torticollis kicked in five years ago and my body language became further compromised by the effects of these movement disorders. The woman who at thirty years old had never felt quite pleased with how she looked even though she satisfied most society's prescriptions for the right appearance, became a shaky middle-aged invalid who looked liked something out of her worst nightmare.

Suzanne Berger (1996), 'the horizontal woman', writes that 'pain bleaches the color of your self' (47). She writes eloquently of her perceived loss of attractiveness and touches on the issues of self-doubt and her concern as to how others were judging her.

I barely recognized myself, the woman in the mirror, who had gained thirty, then forty pounds, from inactivity, stooped over, hair askew from lying down, slovenly, suspicious that everyone wonders, Can't she just take one more minute to make herself look better? (No, I couldn't. It was too hard to stand up) (172).

Glen also spoke very powerfully of the fear he had of how others would react to his changed appearance. He had been a strapping young man who had engaged in very physical work and was proud of his strength and physique. His injury resulted in paralysis down one side of his body which affected both his physique and his gait.
Glen: When I came out of hospital, for about four or five weeks I never went out of the house. I just stayed in the house and wanted to, you know, 'cause I was so [pause] demoralised over the accident and the way I looked and the way I walked and I mean it's okay saying, well, people don't look at you, but they do.

Both Glen and Suzanne Berger point to the fact that other people do not react well to the changes of appearance that accompany and contribute to disability. The following section will elaborate on the experiences my participants have had in relation to the negative attitudes of others.

**Under the Gaze of the Other**

All those from the sample whose appearance had changed observed that other people reacted to them in completely different ways. In my own case I found this to be extremely disorienting. You feel like the same person inside and yet the people around you start behaving in ways that are very disconcerting. Most of the people who visited me when I first hurt my back behaved in the uncomfortable manner that I have observed when in hospital. They shuffle and fidget at the end of the bed and leave quickly, commenting that this is because I must need my rest. Need rest? You have got to be joking. I was metaphorically crawling the walls and was desperate for the distraction that company could bring. But I quickly learned that there were certain people who could not deal with the horizontal, pain ravaged, physically diminished version of me.

Lesley talked at length about the ways in which people's reactions to her changed when her paralysis necessitated that she use a wheelchair and how this, in turn, confused her about how to react to them. She still felt like the same person, but people treated her so differently that she was thrown right off balance in social situations.

Lesley: That's about it. Yes. You've just got this feeling that, not only can they not understand you, you can't understand them any more.

Me: Yeah.

Lesley: Because they are reacting to you so differently.

Me: And so it works both ways, doesn't it?

Lesley: Yes, yes, it does.

Me: Because, they are reacting in such a different way, and then you've lost your anchor, what you used to hang on to. Your expectations are all turned upside down.
Lesley: That's right. You no longer know how to read their body language, and you don't know what someone's seeing when they are seeing you. That's something I've found. If a person is standing in front of me, what do they see? The physical picture. You know, you've known exactly what you've looked like all your life. You know if you are tall or short or fat or thin... but, once I was disabled, I didn't know what people saw any more...

Lesley: I mean, did I look perfectly normal when I was sitting down in a chair? You know, what did people feel when I stood up and tried to walk or when I'm sitting in a wheelchair. I just didn't know what they saw any more and what their expectations were of me.

Lesley's insights show how we use other people, as well as pieces of reflective glass, as mirrors. When people begin to behave differently when they see us, this creates a similar kind of dissonance to that which is caused by catching a glimpse of the stranger in the mirror. Yet, unlike the mirror which produces sharp edges around an image that we can gauge subjectively, Lesley points out that you can be left wondering what on earth other people are seeing when they react the way they do.

Aaron also talks about the very different and disturbing treatment he received from people once he became blind.

Aaron: Well, I mean, when you have a physical disability that is very obvious to other people, it's very interesting to see the way that other people treat you.

Me: Yes, and how is that? That's a big part of what I'm looking at and what I've experienced myself.

Aaron: There are people that can be... especially for blind people [Aaron talks about people who will grab his arm and forcibly try to help him across the street]. It's very difficult, because even though sometimes the treatment that you get is terrible, behind it there are very good intentions. It makes it difficult. One of the things I believe with disability, and if you look at the way it's all portrayed, especially in the media and in films and that, is it's one of the worst things that is ever supposed to happen to you.

Me: Yes, exactly. It's portrayed so negatively.

Aaron: It is, and most people, they come up and... oh I couldn't cope if I was you, you do so well, blah, blah... and, again, good intentions, but what lies beneath that is... I can't think of the right word at the moment... but a real disgust for your actual condition, and I'm saying disgust at the moment for want of a better word, that you have this disability, because that's how they treat you to begin with. They treat you as the disability first, rather than treating you as a person.

Me: Yeah, so you've got this barrier between you and people that has to be bridged.
Aaron: That's right, and you also know that people are extremely uncomfortable around you ... What they forget, and, as I say, a lot of this comes out of good intentions, but, if you're doing something like, I get frustrated because all I'm doing is going down to pick up the groceries, but people say, isn't it great, you're doing that and blah, blah, blah and I think, well, they think that's a great achievement for me and it's like, isn't it great I can do something simple for myself? You know, I think you're fantastic ... I guess the patronising behaviour makes you feel small and little.

What Aaron illuminates here is that when an impairment is visible, people see this first and assume all kinds of things as a result. The person's identity is subsumed beneath what it is that people think is representative of the condition of being "disabled", although ironically these attitudes themselves are disabling. Aaron, although he has distinct limitations and needs, has learned to be highly mobile and lives a satisfying life which includes working in a challenging career, studying at postgraduate level, socialising and enjoying a good relationship with his partner. Yet, he is continually jolted back into an uncomfortable space when his disability is focused on above all else and is assumed to be 'the one of the worst things that is ever supposed to happen to you.’ Karen internalised these very attitudes and said that 'I kept thinking that [the wheelchair] was all they saw first. They didn't see me’. Adrienne talked about similar attitudes. People's behaviour toward her changed dramatically as she became more visibly disabled. She expresses the opinion, like Karen, that people only seemed to see the wheelchair, not her.

Adrienne: I went from being a walking person to a person in pain to a person using a rolling walker to being a power wheelchair user and the whole time I was riding the bus... and it was just terrible. People who would never give me the time of day when I wasn't visibly disabled would talk to me. Everybody would talk to me when I was visibly disabled.

Me: Oh, is that right?

Adrienne: But, they weren't talking to me. They were talking at me.

Me: Oh yeah.

Adrienne: They were taking their assumptions and just sort of rolling through... oh it's so wonderful they let you out of the house [laughing].

Me: Oh, that whole patronising thing.

Adrienne: Oh, it's amazing! And people patting me on the head.

Me: Oh really.
Adrienne: Oh wow. It was stunning. People patting me on the shoulder, which was unfortunate because...

Me: ... its very painful.

Adrienne: And, oh yeah, I saw you on the bus last week, didn't I? And then we'd kind of go through detail by detail and it turns out that the person was six inches taller than me and black and had a manual wheelchair...

Me: Ah.

Adrienne: So, that was you on the bus.

Me: Oh yeah, right. That was, all of a sudden, how you were defined.

Adrienne: Exactly.

Me: The main defining...

Adrienne: There wasn't a person in the chair. There was just the chair.

Nancy gives similar examples of the kind of treatment one can expect to receive when using a wheelchair. She believes this happens because the wheelchair user is literally on a lower level. ‘Often, your nose is only just coming above the counter, isn't it?’ Nancy believes that this leads to a feeling or discomfort and even fear. ‘I think it's a slight apprehension. Ooo, we don't know anything about this.’

Nancy: Another friend of mine in a wheelchair, and a couple of upright people... we've got a very good theatre in Christchurch. So, we went there one evening and we'd come in after the show into the foyer and the rain was just pelting down outside. So, the two people who were upright were going to bring the van right to the back door as we were going to, you know, get wet going to the car park and that. It seemed a pretty good idea. So, [Alice] and I were there in wheelchairs and a woman came up and put her hand on my shoulder and said, and did you enjoy that dear? So, I said, well, I did enjoy it actually. Oh, she said, and where have you come up from? And I said, we have not come up from anywhere. I said, this is not our annual treat and she looked really taken aback. And I didn't pursue it, but if I had pursued it, I would have gone on to say, you see that good-looking guy just going out of the door over there. Would you go up to him and put your hand on his shoulder and say, did you enjoy that, dear? Because, if you wouldn't do it to him, why are you doing it to me?

Me: Exactly, it's so patronising.
Nancy: Another time I had to go to the dentist and St. John's ambulance had arrived. I had to go to the dentist and I was in a push wheelchair. So he pushed me into the waiting room and the woman at the reception desk, it was right across the waiting room where everyone was sitting. She called out, what time is her appointment? So, I called out two o'clock. She totally ignored me and sang out, what time is her appointment? And, it was just spontaneous, I said, excuse me, I said, it's just our bodies that are paralysed, not our bloody minds, you know.

Me: Oh, well said!


Like the former MS Society welfare officer who says to Ellie and me one day when she was visiting, 'The condition will impair his cognitive faculties.' We're both gobsmacked. Ellie recovers first and ripostes, 'how am I supposed to tell?' We're getting used to shite like that, even from so-called experts. 'And how's he getting on?' people have been known to ask Ellie, when I'm sitting in my chair right next to her. 'Blowed if I know,' she says. 'Why don't you ask him? He's around somewhere. If you hang on, I'll give him a yell.'

Dis-abled. Not-abled. Unabled. Reduced to a one word description. How many people do you know who are described by one word? Unless it's a joke like the balanced accountant, the level-headed carpenter, the sparkling electrician, most people are afforded at least a crude attempt to encompass the breadth and complexity of their being. But not if you're in a wheelchair and need a hand with a few things. Then you're disabled, and woe is you, if, like me, you sound like you just got off the special bus. You're not only disabled, you're intellectually handicapped as well. That's when people bend down to you and talk really loud, often referring to you in the plural.

'And how are we today?' they ask

What can you say? 'Well, these guys are okay, but I'd watch those blokes in the striped jumpers. They seem intent on causing trouble.'

Even some of the staff in the Lesley Groves home say it. 'And how are we today?' I'm at their mercy so I bite down hard on the smart replies, and refrain from looking around with a puzzled expression. 'We're doing fine,' I say. 'Box of fluffies.'

'That's good. Do you need anything?' (4-6).

The stories are endless. Most of the participants with visible disabilities spoke or wrote about the patronising reactions they received from those around them. It is not possible to share them all in full, but I will attempt to paraphrase some of them. A. Manette Ainsay (2001), who is a power wheelchair user, gives numerous examples, but one particularly compelling one concerns a visit to the post office. Her mind is filled with the complexities of the day ahead and she begins to plan a grant proposal she needs to write later that day. Out of nowhere a woman addresses her: 'You seem awfully young to be in one of those things, she says, mournfully. Is it
permanent?’ What clashed the most discordantly with A. Manette Ainsay’s reality was that the stranger saw only the disability and felt pity for her, while she was in fact engaging in a very positive and complex life and could not be feeling less like an object of pity (183).

Albert Robillard (1999: 72), Alana Arnot (1998: 172), Marjorie Wagner (1986: 61), Joni Earickson (1976: 110), and Kevin Hitchcock (1998: 211) in their autobiographies, and Greg, Craig and Jane in their written stories, all gave examples of their companions being addressed instead of them. Many of them connected this treatment with being considered a ‘mental defective’ and Alana Arnot (1998) wrote of the pain and shame that came from being stared at. She wrote: ‘I despised myself this way and I felt like a carnival freak show’ (172). Alana’s words point to the fact that these patronising and alienating behaviours do not occur without effect. And it would appear that the most salient emotion that disabled people felt in response to the way that people reacted to their appearance, as with becoming dependent, was shame.

Disabled by Shame

Shame is the recognition of the fact that I am the object the Other is looking at and judging.

Jean-Paul Sartre

Shame: The painful emotion arising from the consciousness of something dishonouring, ridiculous, or indecorous in one’s own conduct or circumstances or of being in a situation which offends one’s sense of modesty or decency. Disgrace, ignominy, loss of esteem or reputation.

Oxford English Dictionary

Feelings of shame can arise from one’s inner sense of inferiority or from the disabling treatment of others. Yet, in either case, they are embedded in social foundations because, if it were not for the stringent standards against which one was encouraged to measure oneself, then shame would not be incited. We feel shame when the realities of our appearance are so out of phase with what is socially acceptable that we feel grotesque or looked down upon. With the exception of Glen, who admitted that when he came out of hospital he felt ‘demoralised’ about the way he looked and walked, and Lee Trustrum, who elaborated on the discussion of shame that she launched in her written story, statements of shame only came from within the autobiographies. I believe that the reason for this is that shame is too painful an issue to bring up in conversation. Lee Trustrum talked about this in one of our dialogues. Although her genetic disability is largely invisible, she has experienced a great deal of shame at her physical difference. She speaks of disability-related shame in the following excerpt.

Lee: [Shame is] terribly insidious. It just works it’s nasty little ways in everything. It dabbles its fingers in the whole development of the kid. Especially for small people, I
think ... children naturally feel inferior to adults because they don't know much, they go
to bed early, they have to be looked after, all that sort of stuff. And, we tend to grow out
of that, but that feeling of inferiority, if it lasts, particularly beyond childhood is, in itself,
an admission of inferiority and that's the shame. So we are ashamed of the shame and
that's why we don't admit it...

Me: Because you're not supposed to feel like that.

Lee: No. Well, if you feel like that, then you must have something to be ashamed of and
that's awful, so then you can be judged. So, that's another convoluted one I think.

Me: Yes, where it feeds on itself. It's very complicated and therefore difficult to get to the
source of it.

Lee: Yes, and I think that's why people are often not aware that it's there.

Me: Because they bury it for that reason because they can't acknowledge it.

Lee: Yes. Yep.

What became clear during this conversation was that we are often hesitant to admit to shame
because we are too ashamed to do so. At least if we can act like we are coping well, no one will
know how deeply scarred we are by our experience of disability. Those, however, who could
distance themselves through their writing tended to point to shame as one of their strongest
emotions in relation to their changes in appearance. Jill Sager (1986) writes that: 'I don't like my
body. I'm ashamed of my body. I treat my deformed leg like an "it," not a real part of me' (198).
Jill has deeply painful memories of attending a mainstream school.

Attending a regular school in a health class meant being the first class to enter the
school auditorium for Friday assemblies. For two years every Friday morning I made that
long and dreadful walk from the elevator into the school auditorium. It meant walking
past all the other fifth and sixth graders as they were getting into lines preparing for
their walk into the auditorium after the nine of us were already seated. Every week we
walked in single file in front of the rest of the school while they stared and we tried not to
feel different.

But we were different and they wouldn't let me forget that 'different' meant I should feel
ashamed. I couldn't feel OK about being different because I felt too abnormal. I was too
aware of the clanking of my leg brace. I was too aware of the visibility of my back brace.

Every Friday I felt embarrassed for who I was, and that feeling never disappeared until
the assembly activities were under way (197).
Reading this excerpt again brings to mind a conversation I had with one of my participants. Susan talks about how the university she works for does not have adequate modifications to facilitate students and staff members who have disabilities. There are no special parking spaces and there are no accessible toilets on her floor of the building. Everyone else walks up the stairs to the next floor to use the toilet, but Susan, who does not have this choice, must use the toilet that is usually only accessed by those in the music room. She explains how embarrassing this is.

Susan: Yeah. It's just crazy. And my choice is, disturb all the people playing music... we're talking about semi structured orchestras here...

Me: Gosh!

Susan:... and conductors and people singing opera and not the sort of people I would usually deal with and you're a sort of knocking on the door and opening the door and zooming through [on an electric scooter] and apologising like mad, keeping your head down because you are so embarrassed.

Susan is not talking about experiencing deep feelings of shame here, but she is forced to feel extremely uncomfortable about having to draw so much attention to herself in front of all those people. Unlike her able-bodied peers, she has to go through this embarrassing routine every time she needs to go to the toilet, and, like Jill Sager, she feels like the centre of attention when she just wants to blend in and go about her business. Melissa Anne Goldstein (2000) writes about the shame she has had to deal with in relation to the myoclonic attacks (epilepsy) that have been brought about by lupus.

Occasionally I broke out into myoclonic attacks in which my hands, arms, legs, and even my head would jerk or spasm uncontrollably, sometimes violently. My face, including my eyelids, also fluttered and tremored. Sometimes only my face might be involved, just one side of my body, or single limbs. As I shook, a little girl, maybe about four or five years old, pointed at me and said loudly, "Mommy, why is she doing that?"

I knew that she was only a child. I should not be angry or hurt by her understandable curiosity. But at that moment she seemed cruel. I felt humiliated enough by my spasms (7)

... even though the rational, intellectual part of me knew that seizures should not be viewed differently from any of my other symptoms, so powerful is the stigma of epilepsy, I could not help but feel a lingering sense of shame and embarrassment about the seizures (222).
Max Dashu (1986) also writes about the shame she had to learn to deal with in relation to her epilepsy. Like some of the others (cf. Gallagher 1998) she writes in the third person to distance herself from her pain.

She felt people on the bus staring at her. It made her feel more restless: claustrophobia. She looked out the window and thought how unnatural she must look - too jerky, and how she should try to look more normal - blend in somehow. Camouflage was her life strategy in these situations. Moira was disgusted with the watchers but dissatisfied with herself anyway. Most people are terrified of epilepsy, its dramatic interruption of social convention. Nervous disorders carry a special stigma because they affect behavior. Very close to insanity. People are threatened by physical movements with no apparent reason. Twitching, jerking, blankness - or full-scale convulsions ...

Moira began to attend to herself and work on the shame. She knew what kind of looks to expect, but she picked herself up with dignity. She worked on her own confidence. She had to chisel through the layers of grotesqueness that coated her self-image (203-204).

Eli Clare (1999) whose disability also involves involuntary movements writes about her shame in the strongest terms possible.

I think about my disabled body. For too long, I hated my trembling hands, my precarious balance, my spastic muscles so repeatedly overtaken by tension and tremor, tried to hide them at all costs. More than once I wished to amputate my right arm so it wouldn't shake. Self-mutilation is shame of the baldest kind (130).

My own experience with movement disorders is one which has caused such deep feelings of shame that it is generally an unspeakable issue in my life. When tremour and dystonic movements entered my physical repertoire, I was mortified and I learned quite early that to talk about it or in any way draw additional attention to it made things infinitely worse. I am currently in a state of remission where my hands only shake when I am under stress or when trying to engage in something which requires a degree of fine manual precision and the torticollis (neck twisting) is, I believe, only mildly observable. However, when the torticollis first became apparent five years ago I was not in possession of the management strategies that I have since developed and I was constantly finding myself in situations which left me feeling like a freak. I remember searching on the internet to find out more about my condition and I saw photos of the most extreme versions of torticollis where the person's head is pulled down onto one shoulder by the muscle spasm on that side. It was there that I read about how people with torticollis had once been locked up in mental asylums because their body language had made them appear insane. I cried for a long time over my initial discoveries and I still live in fear that my virtual remission will end and that I will be thrust into full blown torticollis and tremour again.
Suzanne Berger (1996) writes about the shame which accompanied the stares she received when she needed to lie down in public: the particular shame of “the horizontal woman”.

But then someone started to stare. Being stared at somehow creates a sense of shame, as though the soul suddenly assumes a face and must hide it, turning away wordless, cast off. And how could I allow another stranger, this time a well-dressed, all gray businessman, to cause such commotion for me? Even with the wheelchair there, for context, the eyes of people still searched me out. What is that woman doing lying in our bar? This time I stared back, forcing boldness out of its hiding place. It was an animal confrontation: I was also asking for mercy. Please, I am asking you, do not violate me. I know I look odd, but get on with it, accept it. I wanted to punish him, for his face to go slack with embarrassment. He just walked away (132).

Robert Murphy (1990) analyses the shame experienced by disabled people, particularly those who use wheelchairs.

Shaming is an especially potent means of social control in small-scale societies, where everybody is known and behavior is highly visible, but it is less effective in complex societies like our own, where we can compartmentalize our lives and exist in relative anonymity. But a wheelchair cannot be hidden; it is brutally visible. And to the extent that the wheelchair’s occupant is treated with aversion, even disdain, his sense of worth suffers. Damage to the body, then, causes diminution of the self, which is further magnified by debasement by others.

Shame and guilt are one in that both lower self-esteem and undercut the facade of dignity we present to the world. Moreover, in our culture they tend to stimulate each other. The usual formula is that a wrongful act leads to a guilty conscience; if the guilt becomes publicly known, then shame must be added to the sequence, followed by punishment. There is then a causal chain that goes from wrongful act to guilt to shame to punishment. A fascinating aspect of disability is that it diametrically and completely reverses this progression, while preserving every step. The sequence of the person damaged in body goes from punishment (the impairment) to shame to guilt and, finally, to the crime. This is not a real crime but a self-delusion that lurks in our fears and fantasies, in the haunting, never-articulated question: What did I do to deserve this? (92-93).

Against all this, if one was not aware of being viewed as unacceptably different, then shame would not be an issue. For example, Lucy Grealy (1994), who had most of her jaw removed because of cancer early in her adolescence, did not think of her appearance as unacceptably different for some time. She had always been proud of her tomboy appearance and wore the scars of her operation with pride as badges of courage. Eventually, however, the reactions of others began to make her realize that her appearance was being met with aversion.
One morning I went into the bathroom and shut the door, though I was alone in the house. I turned on the lights and very carefully, very seriously, assessed my face in the mirror. I was bald, but I knew that already. I also knew I had buck teeth, something I was vaguely ashamed of but hadn't given too much thought to until this moment. My teeth were ugly. And, I noticed, they were made worse by the fact that my chin seemed so small. How had it gotten that way? I didn't remember it being so small before. I rooted around in the cabinets and came up with a hand mirror and, with a bit of angling, looked for the first time at my right profile. I knew to expect a scar, but how had my face sunk in like that? I didn't understand. Was it possible I'd looked this way for a while and was only just noticing it, or was this change very recent? More than the ugliness I felt, I was suddenly appalled at the notion that I'd been walking around unaware of something that was apparent to everyone else. A profound sense of shame consumed me (112).

The same humiliating sense of revelation hit Kenny Fries (1997) when he reached his adolescence. As his disability did not severely affect his physical abilities he attended a mainstream school and did not consider himself different in any problematic way.

When I was young, I performed: I sang, played the piano, acted in plays and musicals. But by the time I reached high school, something began to change. One afternoon, coming home from school, as I reached for my keys, I noticed the reflection of the full-length of my body in our apartment building’s glass front doors. To my surprise, the reflection that confronted me in the glass was not the image of myself I saw in my mind. Did what I see reflected back to me correspond to how others perceived me?

For months, I could not get rid of this image: my asymmetrical body lurching forward with each step. Although I never told anybody, I became self-conscious, felt my deformity was too obvious, drew too much attention. Disabled, I felt everybody’s eyes - like the boy who asked me about my legs, the kids who would call me midget - were transfixed on my legs. What was I doing on stage? I felt like a fraud (22).

It is significant that both Lucy and Kenny became ashamed of their difference when they reached adolescence. This is often a time where the building of a comfortable identity relies on being able to fit in. Only then can one feel safe to make choices that lead to voluntary differences. People who are disabled in adulthood already know about the discrimination that accompanies certain changes in appearance and, as a consequence, they often experience shame from the outset. Yet, for children, who often perceive the reality that everyone is different anyway, what it is that constitutes unacceptable difference is learned by cold, hard experience over time.
Intimate Losses

I feel teardrops trickle through
nearly half a century
For the loss of touch.
Is it something gentle,
warm, intimate, exciting,
Being touched?
Does it contribute towards
that feeling of
Being loved?
I taste the saltiness of tears
engulfing the years
For the loss of sexuality.
Is it something sensual,
self-defined, empowering?
Does it allow the sensitivity
of being a woman
To be acknowledged?
I expose a stormy outburst of emotion
taking almost half a century of anger
For the loss of relationships.
Are they something experienced only by
non-disabled people?
Belonging, being welcomed as
part of family, community, society
Let me give expression to
Almost a lifespan
of isolation, of painful separations.
Let me not be ashamed in grieving
for the loss of touch,
love, sexuality, personal growth
As I search and reach out
for inclusion.

Ann McFarlane

Closely related to the experience of developing an unacceptable appearance and the resultant rejections and feelings of shame, are those losses which can adversely affect a disabled person's sexual identity and his or her capacity to establish and maintain intimate relationships. Many people from the sample who were single at the time they became disabled, as well as those who lost their partners as a result, worried that they would not be able to attract another partner. Many of those in relationships expressed concerns about how their appearance made them uncomfortable or self-conscious about sex and some pointed to the belief that their choice of partner had narrowed considerably because of the effects of disability. Living in a society
which glorifies the attainment of "love" in its ideological form as a union which is purported to provide such diverse rewards as romance, companionship, affection, financial security, interdependence, sexual satisfaction and children, means that those who are perceived as unworthy of this kind of love can feel that they are losing out on a great many levels. Sexual desirability, influenced as it is by cultural imagery which privileges a certain kind of physical "perfection" and athletic prowess, greatly affects the potential for a person to find and preserve these intimate relationships based on "love". The losses in this area, touched upon by many, are extremely painful in the sense that they affect very vulnerable and private areas of one's identity.

Take, for example, Jeni Fulton (1995) who writes that in every other area of her life she has been able to become strong enough to challenge the norms that originally disabled her. Yet, her doubts in relation to her physical and sexual identity have become more intense.

Disconcertingly, my unhappiness about my body has grown as I have become increasingly political about being a disabled person. In other areas of my life I have become more assertive and confident about who I am, an important part of which is me as a disabled woman. I am, after all, a woman with a happily independent life, a beautiful home, a ridiculously senior job. Yes, I can say proudly, that this is me, despite the ways society tries to deny me the competence I have, tries to make me invisible, put me down, patronise me, exclude me, deny me my civil rights. Mostly I am strong enough to get politically angry, to challenge and continue to grow. Hard as it sometimes is, I really enjoy that part of the journey.

Then I see myself naked in the bathroom mirror, and suddenly that sight redefines me. I wonder if the politics help me avoid what I have to do in challenging my relationship with my emotional and physical self. I want to make progress in that relationship as I have done with my political self, but if I can't like my body, love it, be kind to it, how can I expect anyone else to feel differently about it? I'm so out of practice that I can't imagine what I would do now if I wanted to seduce someone. Others see, fancy and proposition - a usual course of events. I couldn't even approach that. I would have to embark on a full discussion - what my body is like, how I'm restricted, and so on ... and so on... and so on. Some seduction! Or I could just grab the condoms from the bathroom cupboard (hoping they're not past their sell-by date - very likely by now, I'm afraid), and risk him recoiling in horror. Perhaps it would be easier with a relative stranger, rather than with a tried and trusted friend where there would be so much more to lose ... (87).

These intimate revelations indicate how deeply disturbing and difficult to resolve are the issues which stem from the disabling of a person's sexuality and their opportunity to engage in sexual relations. The nature of this identity loss and its isolating effects will be the focus of this section. Firstly, however, the fact that many disabled people are assumed to be asexual, altogether lacking in sexual identity and needs, will be explored.
The Loss of a Sexual Identity

While many people talked about the concerns they had for finding new partners or of holding onto existing ones because of the fears they had developed in relation to their appearance and sexuality, some felt like their gender and their sexuality had been completely neutered. It was felt or discovered that when one has lost the attributes perceived to be necessary for sexual attractiveness, then others come to believe that a sexual identity is no longer relevant. Adrienne talks about the discordant response that her naturally flirtatious nature now receives.

Adrienne: And I know for one thing... I'm an uncontrollable flirt and I will flirt with people, I don't even know I'm doing it, you know, and I've had bus drivers, when I get on the bus, they use things that are called "tie downs", kind of sexual there, to tie my chair to the floor of the bus...

Me: Okay.

Adrienne:.... and some of them have kind of "come alongs"? Where you move something back and forwards to tighten it.

Me: Right.

Adrienne:.... like to lift a heavy load like a motor...

Me: Oh yeah.

Adrienne:.... and so, I remember when this guy was sort of going, oh yeah, okay, got it now, and I said, was it as good for you as it was for me? And it took him, I could just see it, like, oh wait a second, she is flirting. Gee, people like that flirt too? You know, I mean, it just hadn't occurred to him.

Me: Yeah.

Adrienne: And that's really annoying.

Me: It would be.

Adrienne: And it's like, oh my God, and that was one of the areas where I just knew I was confident, even when I was young and in the sway of my crazy family, I was confident that I was the bees knees when it came to sexuality and so, to have that undercut by vuvdynia, undercut by the change in my appearance and the change in assumptions that people have...errrr. Errrr, I don't like it.

Craig also talked about the threat of losing his sexual identity and how this made him react in what he considered to be a promiscuous way.
Craig: The problem was that there was an exaggeration because of my disability and well, okay, there was the sex thing and all that kind of stuff... simply because I felt so inadequate with my disability. You were so afraid of everything and you also desperately craved - that was the other thing too - with the disability and all the rest of it, you desperately craved to be treated as normal. And so it was the party scene and the sex thing and that was all part of it, because everyone else was doing it in the Sixties.

Chris Baker (2003), in a story he sent me recently, which is tellingly called *No Sex Please, We're Disabled*, focuses on how life in a nursing home tends to render one, in the eyes of many, a non-sexual being.

Sex is really a no-go area here in the Leslie Groves Hospital. I mean, here are us residents, wheelchair-bound and utterly dependant on the nurses for the most intimate functions like bowel motions and catheter changes, lying back and thinking of the queen while we get put to bed, got up, showered, dressed and undressed (1).

It probably helps you to survive in this vale of tears generally and here in particular to have a good awareness of your own sexuality. In fact, if you’re disabled you’ll need that awareness, especially in the interests of surviving society’s prevalent attitude towards disability, for which you can probably substitute the word ‘disqualification’. In other words, how dare you view yourself as a sexual being? You’re less than physically perfect and the thought of you in the throes of passion is utterly distasteful to any ‘normal’ person (4).

Eli Clare (1999) writes about being treated as asexual, genderless.

It is no exaggeration to say that we are genderless, asexual undesirables … On the one hand, disabled people mostly escape the sexual objectification and harrassment many nondisabled women face every day at their jobs and on the streets. It is an escape that has given me a bit of space. Amidst all the staring I absorb and deflect, I am grateful not to have to deal with sexual leering. On the other hand in the absence of sexual gaze of any kind directed at us – wanted or unwanted – we lose ourselves as sexual beings. I almost don’t have words for what this absence, this loss means in my life. It has been a gaping hole, a desolate fog, and a “normal” everyday fact. It has translated into an inability to conceive of myself as attractive and desirable, has added to my sense of being ugly and clumsy. I hate these meanings (113-114).

Suzanne Berger (1996) recalls an incident where, like Adrienne, she is jolted into the recognition that strangers no longer view her as an object of sexual interest.

Part of femaleness, but only part, is feeling an animal possibility, the elation of possibly attracting new sexual interest, with the potential of acting upon it, even if there’s no real desire to carry through. With chronic pain, clumpy sneakers and a cane or wheelchair,
erotic possibility felt canceled, or at least for me, and with that, my femaleness partly canceled too. No one seemed a possible lover because no one saw me that way. Not to be looked at longingly anymore; of course that is the hard truth of the past tense: We were all beautiful once. But in me the sense of lost attractiveness had been sped up. Stolen were those accidental glances from strangers that as contemporary women we are not supposed to want …

I am getting into a car, quite a spectacle in itself: cane thrown in first and body "bent" as much as possible to get in the back door, lying on the mattress the goal. But before that, a dignified, unusually handsome older man looks over in my direction; will the glance smolder or deepen? I hope. Then I hear from his lovely plummy mouth, Can I be of assistance to you? End of the imagined sensual drama. I was not seen, except in terms of needing help. Agh, we are not beautiful anymore. I am seen as an extension of my stupid cane, my shoes, my awkwardness, doctor. I had been unsexed in my image of self, and no healer can (or should) "re-sex," exactly as no healer can truly revitalize the truly anemic spirit in a series of office appointments (172-173).

The Loss of Sexual Desirability and Relationship Potential

Whether one is seen to be asexual or an unappealing example of one's gender, the reverberations reach out to affect the potential to engage in intimate relationships with significant others. Some, like Angus, feel that disability cancels out the possibility almost entirely.

Angus: God, and how do you get to know somebody when you're incapacitated? I guess it's not impossible, but it's... [pause]...

Me: Intimidating.

Angus: Yeah, and I just can't see how it can happen without me making a lot of changes and it all just seems to be too hard.

Glen talked about how he had felt that marriage was out of the question for him after his accident.

Glen: And you start thinking then who's going to marry, who wants to go out with a bloody old cripple? You know how things go through your mind.

Me: I felt like that.

Glen: And once you start feeling like that you get down in the dumps.
Karen names the time in her life when she began to desire boyfriends in her late adolescence as the most damaging to her identity. Prior to that she had not seen herself as unacceptably different and her family had included her in everything. She was not prepared for the insecurities that come to the forefront when she started meeting boys.

Karen: I was very scared that when it came to personal life, you know, boyfriends... I mean, they may have been saying to you that this is not working for normal reasons, but I didn't believe it.

Me: Look, I know exactly what you mean.

Karen: I believed it was because I was in a wheelchair. So I kept thinking that that was all they saw first. They didn't see me. Like it came to you like a shock really. I'd sort of... right up until that point you cruise along with life and have your fun and all this and then you realise that you have all these emotions and feelings and, you know, that other people aren't going to see them the same because you are different. Especially guys, for me, being a female, wanting boyfriends, relationships, that sort of thing. It starts making you question yourself mostly.

Me: Yeah, because there is a difference... there is like a gap there, isn't there, between how you see yourself and how you feel that other people are going to see you. There's this gap and you can't bridge this gap. That's the fear, isn't it?

Karen: Yeah, and it's very powerful and, no matter how level headed I thought I was, it still controlled me. Probably, right up until about fifteen or sixteen years ago, really. It was really uncontrollable, really powerful, because it was how you wanted people to perceive you, but in your mind he knew that they didn't perceive you that way.

Lisa Reid (2001) endured very similar circumstances.

An even harder thing to cope with was growing up and becoming a woman. I felt like no boy would ever fancy me, or love me, because I was different. That age is hard enough as it is, coming to terms with all the changes to your body and mind without the added difficulties of disability. From being a cheerful joker, I became very withdrawn and depressed, and I hated that (45).
Ruth Seinkiewitz Mercer (1989) tells how her hopes of ever having a relationship with an able-bodied man were dashed.

Shortly after our date, I asked Hans to the prom, and he readily accepted. During one of our conversations about it, he started telling me that he thought I was a beautiful woman with a good mind locked up inside an unfortunate body. He said that he liked me very much as a friend, but he didn't think we would make a very good match romantically.

I understood what he was saying, and I was heartbroken. For the first time in my life, I realized that I would never be able to enjoy a romantic relationship with a "normal" man. It finally dawned on me that no nonhandicapped man would ever be sexually attracted to me - certainly no nonhandicapped man to whom I was attracted, anyway. Since I had never been physically attracted to men with disabilities like mine I concluded that I would never enjoy a sexual relationship with anyone (190-191).

Lucy Grealy (1994) writes about her feelings of self-doubt and how they were reinforced by the responses of men.

In the wake of my recurring disappointment I'd often chide myself for thinking I'd ever be beautiful enough, good enough, or worthy enough of someone else's love, let alone my own. Who cared if I loved my own face if no one else was going to? What was beauty for, after all, if not to attract the attention of men, of lovers? When I walked down a street or hallway, sometimes men would whistle at me from a distance, call me Baby, yell out and ask me my name. I was thin, I had a good figure, and my long blond hair, when I bothered to brush it, was pretty. I would walk as fast as possible, my head bent down, but sometimes they'd catch up with me, or I'd be forced to pass by them. Their comments would stop instantly when they saw my face, their sudden silence potent and damning (188).

Jane wrote at length about her feelings of unattractiveness, her despair at ever finding anyone to love and her feelings about her sexual experiences since becoming chronically ill.

Body image is so closely tied in with sexuality, probably because both are such intimate feelings. I don't get out much, so my chances of meeting anyone right now are minimal, and even if I did, I wouldn't have the energy to even talk about sex!! I remember when I first became ill, and my boyfriend at the time and I were in the infancy of our relationship. We hadn't yet had sex, and he asked to see me naked. I burst into tears, because I felt I had more of a chance of painting the ceiling of the Sistine Chapel than standing there naked under what I felt would be intense scrutiny. I went home alone that night. He later told me that he felt hurt that I couldn't trust him enough. I felt hurt that he'd even requested it of me ...

I went through a period about six months ago when I became convinced that I'd never have sex again, and that I should grab it if it ever came along. After all, being ill and
overweight doesn't mean that you stop feeling sexual. An old friend (actually the first love of my life) popped back into my life, and things turned sexual, which I was really pleased about. I put myself through some awful pain, but the payoff seemed worth it. Now I feel that unless there's real feeling and respect there, I'm not going to sell myself so short. Sure, the intimacy of being so close to another person can't be replaced by much, but the feelings of near-depression when he popped out of my life again weren't worth it. (written story: 2).

In many cases, existing relationships did not survive disability and illness. In some circumstances this was because the disabled person made the decision to break up with an existing partner because they believed that the disability made being loved and found attractive impossible. Lois Anderson (1986) wrote about how her 'hopes went down the drain' and she decided that she could not continue her previously very successful and satisfying relationship.

Looking at myself in that big water and sand bed I saw a body so horrible looking. I started thinking about the three wonderful years I spent with my boyfriend before this accident. What was going to happen to me now? I loved him and wanted very much to keep him, but I gave up my relationship. My hopes went down the drain. I had to give him up. I knew I was the same person in my mind, but my body kept telling me it would not work out. I felt I could not give him what he needed. I felt that my sex life was over (276).

Jacky also broke up with her fiancé when she became disabled for reasons that she eventually began to question.

I also felt thoroughly unlovable and unable to share any emotion with those close to me (except sometimes crying because of physical hurt). I broke off my engagement - my reason being that I 'was no longer in love' - but, now I see that I was just 'letting him off the hook' since I didn't feel of any worth (written story: 3).

In Alana Arnot's (1998) case, her husband eventually left her. They had been aerobatic pilots before the plane crash that disabled her and he found it impossible to accept the change in her. Alana writes about the clash between her and Nigel when she finally accepted the permanence of her disability but he could not. Nigel comes in when she is packing up her high heeled shoes.

'No, don't touch them;' he said. 'Leave them right where they were.' He took a shoe out of my hand and put it back in the cupboard along with the rest from the bag. I was dumbfounded. I felt like an impostor. It was as if they weren't my shoes to touch. Nigel was still holding on to the beautiful, fit and active woman I had been before the accident. He wasn't ready to come to terms with letting that person go (195).

Nigel did not adjust, however, and Alana tells of how the strain between them grew.
Mum and Dad came over to our house for dinner to celebrate Nigel's win on the night he came home, but he seemed depressed and preoccupied.

'What's wrong with you?' I finally asked.

'I didn't want to come home to you and this nightmare. Our future is so uncertain,' he said.

I put my head down. I couldn't bear to look at Mum or Dad.

Well, at least you're honest,' I said. My injuries were a life sentence but if I could walk away from them, I certainly would. I never wanted to be a burden on Nigel and never wanted to see myself as his invalid wife, but that's how he made me feel. I have never felt more unattractive than at that moment. I felt like half a woman, like a freak. It would have been so easy for Nigel to stay away, and part of me wished he had. I really didn't know why he'd come home (192).

Eventually Nigel left Alana, as my own partner of eight years left me. Unlike Nigel, however, my partner had no patience with my disability at all. He came from a workaholic family and his mother had recently broken her back in a car accident and, after major surgery, had donned a back brace and gotten back to work on the farm. Additionally, our sex life, which had been a very beautiful and constant part of our relationship, became almost non-existent. On the few occasions that we did have sex I felt he was thinking only of his own satisfaction and I lay there in pain, immobile, feeling used and useless. After our break up, there were three years where I did not have a lover. I remember back then thinking that I would never be in a relationship again. I had been an athletic, highly sexual person before my injury and I could not imagine my new body, defined by pain, atrophy and immobility, being either sexually attractive or sexually capable.

The Disabling of Relationships

Those who maintained their intimate relationships or formed new ones after becoming disabled talked about the difficulties that arose. Craig, for example, told me how he was denied the opportunity to marry his first love by a family who believed that his blindness made him an unsuitable marriage partner. He later married a woman to whom he has remained happily married for many decades, but the initial response to their marriage was similar.

When [Marie] and I got married, some said "We give them six months". Not because I was particularly horrible, not because I was unpleasant, but because I was disabled. Family said to [Marie], "He is a nice man, but we hoped you would marry someone that could help you." She pointed out numerous able bodied relations who don't even make their wives a cup of tea, or dry the dishes. I bring [Marie] a cup of tea every morning at 6 o'clock. I set the table. Wash the dishes. Vacuum the house, hang out the laundry, make the bed, cook when [Marie] is unwell, clean bathroom and toilet, but the majority of people think I get waited on hand and foot. [Marie] would willingly do that, but it isn't
necessary. Society however, has preconceived ideas as to what being Disabled and married is (written story: 3).

Albert Robillard (1999) tells of similar attitudes, this time toward a marriage that was already in existence before the onset of the disabling impairment.

After he had changed my tube and I had gotten down from the examination table and was sitting in my wheelchair, the doctor unleashed the following remark, without provocation: "You are lucky you have a wife who stuck by your side. Most people in your condition have had their wives split long ago." Divina immediately replied, facing me, "You see, you see!" … I heard the remark of the physician as a left-handed endorsement of the commonsense reasoning that women married to disabled paralytic men should divorce them. I heard his remark as denigrating life with a paralyzed person. I heard my wife's response as referencing that body of commonsense reasoning (36).

These 'commonsense' assumptions flowed on to other assumptions about Albert's sex life with his wife.

My paralysis leads people to think that I have lost sexual function. It does not matter that my penis is one of the last things working properly. I still experience this assumption, seemingly part of the omnipresent condition of paralytics … This assumption about loss of sexual function, no matter what the diagnosis, is an ideal that assembles what the perceiver sees …

My wife tells me that as soon as they know that she has a paralyzed husband in a wheelchair many men start making advances. She thinks they are motivated by commonsense thinking that she is sex starved. Having a paralyzed husband leads many men to assume that "she is not getting enough" and is an easy mark. These advances come all the time (21).

Ironically, some people also talked of their own mistrust in those who desired them. Lucy Grealy (1994), Arnold Beisser (1989) and A. Manette Ainsay (2001) all said they had doubts about the kind of person who would want to get involved with them. In fact, both Lucy and Arnold drew on the same adage to describe this doubt. Arnold writes:

At the time I was both surprised by and mistrustful of any evidence of interest in me by young women. I thought it proved that there was something wrong with them, as implied in Groucho Marx's famous saying: "I wouldn't want to belong to any club that would have me as a member." I had so many self-doubts, and was so embarrassed about my body, that I was very afraid of disclosing myself. So I kept my relationships with women rather superficial and impersonal. (Arnold Beisser 1989: 54).

Lucy reiterates:
Bent on proving I was desirable, I started collecting lovers, having a series of short-term relationships that always ended, I was certain, because I wasn't beautiful enough. I became convinced that anyone who wanted to have a real relationship with me was automatically someone I didn't want. It was the classic Groucho Marx paradox: I didn't want to belong to any club that would have me as a member (Lucy Grealy 1994: 208).

A. Manette Ainsay (2001) writes of the similar lack of trust she and her family felt toward her new boyfriend.

Still, by the end of December, I had my degree in hand. In addition to this degree, I had also acquired a boyfriend, a nice and decent boyfriend, who no one in my family trusted, least of all me, because if he really was such a nice and decent boyfriend and not some weirdo with a Florence Nightingale complex, then why was he going out with me? (193).

On another level of doubt, Suzanne Berger (1996) began to feel very unworthy of her relationship with her husband and expected that he would want to leave her.

"You could marry someone else, you know." I do mean it. "Try to be more optimistic," you say, but you turn away as you say it, looking out at the confetti shower of snow.

But I will never be the person I was, the woman who canoed, the traveler, the lake rider, the sexual acrobat. I will never be at ease in this body, never believe that it's a good and useful thing, an instrument of pleasure and speed. I am not the woman you married. I am the Other, the one you wheel everywhere. The one whose shoes you tie, the one you will soon watch ascend to the second story of our house, accompanied by the extraterrestrial sounds of the new Chair-0-Later.

The undertow is with us in the room, though breathlessly I am trying to escape it, this drowning sense of sorrow and stupid self-pity. "What are we going to do?" I ask. "How can we go on like this?" I know the answer: the same way we've been doing it (18).

I have experienced all of the above. The man I love, who is now my partner, came to know me after I hurt my back. We were friends for many years and, on many levels he was my saviour as many of my opportunities in life, such as moving from my parental home and starting my own life again, were only possible because of his support, both practical and emotional. Yet, when we began to desire one another I was torn between my deep love and sexual yearning, and my feelings of worthlessness, my belief that he could do so much better than me. There were many able-bodied women who were keen on him, women whom everyone seemed to agree were far more suitable than me, and, as part of my love for him, I believed I should not get in the way of him finding a more appropriate lover and partner. Many years went by where we were drawn
together then flung apart by our uncertainties. It took me a long, long time to develop a
sufficiently strong sense of self-worth to allow me to have a healthy, balanced relationship with
my lover.

My sexual identity was torn asunder by the ravages of my disability. My intimate relationships
had always contained a strong sexual component and I liked being my lover's sexual equal and,
to an extent, feeling in charge of his pleasure. I loved being spontaneous and adventurous and
acrobatic. Becoming immobilised and frightened of sudden movements left me with none of my
old mechanisms for embodying my desires. In trying to cling onto the old me, and in fear of
becoming too unappealing as a lover, I risked injury again and again. Many of my early
setbacks were caused by not admitting to my limitations. It has taken years for me to be able to
share my fears and my constraints honestly and in their entirety. Still, I often long to be able to
do what has become impossible and deep within me lurks the disturbing dilemma, never quite
resolved, that I cannot offer enough to my partner in the realm of sensual pleasure. Once a
confident and competent lover, able to satisfy and be satisfied, I now live on a roller coaster of
uncertainty as to what my body will be capable of from one day to the next, how it will look, how
it will feel and how it will perform.

Kenny Fries (1997) draws from conversations and experiences with lovers to share his
insecurities about his body and his sexuality. In the first excerpt he is talking to another disabled
man, trying to reach an understanding of his own feelings and experiences.

"Do you have a lover?" I ask.
"I did but it didn't work out," he says as he pulls on the lever that will make his seat
recline.
"What happened?"
"I'm not sure but when we tried to live together after a few months it blew up. We were
too different. I'm not sure he ever could have understood my body. My legs have no
muscle left. I never let men see my legs. I drape a towel over them when I get into bed.
It's not easy for two men who want to love each other here. And I'm not pretty with the
polio. I was too insecure. I don't know."

"I never will fall in love again," Dani tells me after a long pause. "I don't want to. It is too
difficult for me."

I tell him about Charlie, the first man with whom I had sex when I moved to San
Francisco. Years ago, when I returned from Israel I surprised myself by asking Charlie
what he felt about having sex with a disabled man. "I concentrate on the good parts," is
what Charlie told me, also answering my unstated question of why during sex he never
touched my legs.
"How did you feel when he said that?"
"I thought he was great to be so honest."
"That wasn't my question."
"I felt as if a whole part of me had been erased" (200).

Neil talked about how becoming impotent had affected his marriage and I reacted with a flood of self-disclosure. Once it became a recognisable theme, I really wanted to ask about my participants' sexual identities in relation to disability, but often it just seemed like too personal a matter to touch on.

Me: Yeah, well, I think that can be a big loss. I mean, I've certainly been through problems in that way. You can imagine with a really bad back, I mean, that has taken away a lot of my sexual ability and that was a big part of my identity and I felt very sad to lose a lot of that and I imagine it's probably different for men than for women. I mean, for a man...

Neil: I don't know. I just didn't feel like I was a complete man and you mightn't have felt that you were a complete woman.

It's true. No matter how politically incorrect it is believed to be, if you can't feel like a 'real woman' or a 'real man', then the potential losses are horrendous. Another married participant, Jack, also wrote that his disability made him feel 'less of a man' (written story: 3). Other people pointed to the physical and emotional discomfort that sex caused after the onset of an impairment. Emily Levy (1986) wrote:

It affects my sexuality because warmth and wetness on my skin makes it itch, and I scratch and scratch and scratch instead of lying peacefully with my lover (28-29).

And Jill Sager (1986) confides:

I feel like I've experienced rape. I don't like my lover lying on top of me when we make love, it's too confining. I feel like I've experienced death many times. Every time I start to have an orgasm I have to remind myself that the lack of control I am feeling is not the 'black hole" I experienced with ether. Sometimes I don't feel different, sometimes it 's all I feel. Everybody treats me different but nobody notices what my difference is (198).

Finally, two participants commented that disability had limited their choice of partners. Aaron expressed this feeling in a conversation that dealt with relationships in general.

Aaron: I guess it's just a completely different thing. When you try to develop intimate relationships with people, it's just very difficult.
Me: It is. Oh yes, it is. For the first three years after I hurt my back, I thought, I probably won't have another relationship again. If I stay like this, I just can't imagine somebody fitting in with that.

Aaron: That's right. And, you know, again, it in some way cuts down on the potential people that you can go out with and that's a sad thing, but that's the way I felt.

Terry, who joked his way through most of the conversation, expressed similar concerns.

Me: So, it sounds like your experience has been a very positive one.

Terry: There have been a lot of positive things. I mean, there's always good and bad, don't get me wrong. I just have this inherent choice of choosing partners. Now, I seem to choose the wrong ones [laughs].

Me: Is that right? I mean, I think that's very difficult anyway. It's very difficult to meet the right person.

Terry: Yeah, for sure. But, my sister made a very poignant comment. Since I've lost my sight, my taste in female company has deteriorated.

Me: Is that right? Why do you think that would be?

Terry: I'm probably a lot easier to compromise on... on what I want. And, of course, you don't get as many opportunities to develop a relationship, so you take what's offered... [pause].

The ways in which disability can affect sexuality and relationships are diverse and very complex. What they all seem to share, however, is that they are linked to the belief that disabled people are either asexual or less worthy as sexual partners and that, therefore, they are less likely to find or maintain loving or otherwise intimate relationships. The social model of disability is premised on the belief that it is not impairments that are tragic, it is the cultural beliefs and consequent exclusions which surround impairments which have tragic effects. I certainly believe this to be true of all the factors which disable the identities of people who have impairments, including those which are based on sexuality and appearance. Yet, even when armed with this political knowledge it is still difficult, as Jeni Fulton (1995) indicates, to translate this awareness into an emancipatory framework within which we can learn to feel comfortable about our differences and to convince others to love us as we are.

**Subverting the Norm Through Challenging Stereotypical Appearance and Sexuality**

Any attempt to subvert the norm is always precarious. For example, any challenge to the belief that people should work for a living leaves one open to various criticisms about dependency and
malingering. Similarly, any suggestion that being in a position of eternal gratitude may be inappropriate can make it sound like disabled people are unappreciative. In the same way, could it not also be claimed that people who challenge society’s stereotypes of attractiveness are merely suffering from a case of sour grapes? I, for example, felt more comfortable arguing against the stereotypical ideal of beauty when I was still slim and young and able-bodied. With the encroachment of age, disability and spreading hips I feel that it can all too easily appear that I am only seeking to justify my own inability to approximate the norm.

While we nevertheless continue to speak out against oppression when we feel that we have little or nothing to lose other than our inferior position, when it comes to appearance and sexuality, there is, indeed, a great deal to lose. In coming out and drawing attention to oneself and one’s vulnerabilities, the losses can be daunting. One can risk forfeiting one’s privacy, dignity and the safety that comes from masking one’s pain and shame. It is not an easy position to take or to even envisage taking. In essence, feelings of shame can severely compromise one’s ability to launch strong challenges against the current ideals of body image and sexuality. Some of those in the sample have nevertheless begun to question these norms and to develop new ways of seeing themselves as a result. In its most elemental form, this entails understanding the tyranny of the norm and how it functions to disable people with impairments. Susan Browne (1986) and Robert Murphy (1990) both touch on these issues.

Feminine beauty is manufactured by cosmetic and fashion industries and changes seasonally. Our self worth suffers when we respond to this sexual objectification. Disabled women have been excluded from patriarchal conceptions of beauty and sexuality. Again, we are encouraged to see our bodies and our selves as distinct. Our beauty is reserved for the inside. Inner beauty is used by our culture as a consolation prize for those it finds ugly. Symmetry, clear eyes, straight limbs and fingers, uniform pigmentation and smooth motions are prerequisites for outer beauty, no matter what else may be popular. People jeer at us. We may not be able to find appropriate clothing for the outside and are advised not to call too much attention to our “flaws” with bright or fashionable adornments. Prostheses, canes, hearing aids, wheelchairs and braces are not designed with aesthetics in mind. Our individuality is not encouraged or appreciated (Susan Browne 1986: 246-7).

It hardly needs saying that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish, however little most individuals may realize them. Most handicapped people, myself included, sense that others resent them for this reason: We are subversors of an American Ideal, just as the poor are betrayers of American Dream. And to the extent that we depart from the ideal, we become ugly and repulsive to the able-bodied. People recoil from us, especially when there is facial damage or bodily distortion. The disabled serve as constant, visible reminders to the able-bodied that the society they live in is shot through
with inequity and suffering, that they live in a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility (Robert Murphy 1990: 117).

People from the sample came up with a variety of ways of challenging stereotypes and negative reactions. Firstly, there were three participants who confronted mainstream response to their weight change. In the following conversation, Adrienne talked about how she redefined her perceptions about her body as her size changed.

Adrienne: Have you heard the word, Zaftig?

Me: What is it? [I don't understand and she repeats it]. No, what is it?


Me: I've not heard it or read it I don't think.

Adrienne: It's a great word. It means that you have enough flesh on your bones to be huggable.

Me: Ah! [Adrienne is laughing]. I like that word.

Adrienne: It's a lovely word. And so I was a zaftig figure.

Me: Oh, that a great word! I've got heaps of friends and family that are going to love that word. They need that word in their lives.

Adrienne: There are lots of people who need that word. [We laugh]. I weighed 130 pounds, 140 pounds. I didn't look like a model, but I was strong. I had lots of muscle and then as I got sicker, I started to take all these drugs which have the side effect of weight gain and I was hanging around the house doing nothing and now I weigh 210 pounds and the weirdness of it is was there was this moment at around 180 pounds where I felt fabulous. I felt, ah, this is the size I should be, even though I had passed into what is referred as morbid obesity in the health universe and so at risk of death from 14 different causes. I felt, oh wow, I had spent most of my teens and a significant part of my twenties and early thirties thinking, I'm so fat and I'd look in the mirror and I wouldn't like what I saw and, looking back on it, I was stunning. What was I thinking?

Me: It's that pressure.

Adrienne: Oh very. Absolutely. I mean this kind of heroin chic... you know the pale ... erk. Anyway, there is this show on TV [etc.. She describes the woman who plays the main role, very tall and skinny and very muscly]. Give the girl a sandwich.
What resulted from Adrienne's rethinking was that she developed a whole new ideal for herself. She discovered a joy in being larger which she found much more liberating than the way she felt when she was under pressure to remain slim while never feeling slim enough. Charlotte expressed a similar resistance to the slender ideal, although her experiences were different. Before engaging in the following conversation, I had just discovered that the medications that Charlotte had to take to help control her illness, Crohn's Disease, resulted in weight gain. I asked her whether this had been a problem.

Charlotte: I've never had that much of a problem, but then again I was always a big kid anyway. It's strange for a Crohny to say that [because Crohn's interferes with what one can eat and causes constant diarrhoea]. I was always overweight anyway. Not by much but enough so that when the prednazone effects did happen I might put on another five or ten pounds, but since I was already big to begin with, it really didn't show that much ... But, as a result of that, what ended up happening was, any time I looked good [when the effects of Crohn's Disease made her lose massive amounts of weight], I felt horrible, and any time I looked bad [had weight on], I felt good. Because, that either meant that I was on prednazone and so I was stable or it meant that I was off my meds and was keeping my weight on.

Me: Oh! Right.

Charlotte: So, as a result, as a teenager it was really difficult, because the only time I could fit into the good clothes, the fashionable clothes, the cool clothes, the clothes that I wanted to fit into, was when I was feeling crappy.

Me: Yes.

Charlotte: And... but, because, when I felt crappy I looked like society's idea of what a teenager should look like, I got all sorts of comments, because I was in the closet [passing as non-disabled], from well-meaning adults, saying, oh, you look so great, you've lost so much weight, have you been exercising?

Me: Mmmm.

Charlotte: And I just wanted to strangle some of these adults.

Me: Yeah. Because, what a combination and what reinforcement.

Charlotte: So, it was just like, okay, so, very early on I learned to... I learned to disentangle how I looked from how I felt about myself.

What is so interesting about Charlotte's case is that, unlike the experiences shared by disabled people in general in this chapter, when she was suffering the most from her condition, she was
closest to fulfilling the norm. As a consequence she was given a lot of praise about her shape when she was actually so ill that she was too thin. Jane writes about another kind of subversive reaction to weight gain.

A part of me embraces being overweight, because I get to be "invisible". I've noticed that as a person puts on weight, there's a point when others seem to look at you as that "fat woman" and wonder how a person could let themselves go like that. It no longer matters that you may be very kind, eloquent, generous and a whiz at canasta (where do I get these things from???:)) because who you are inside can't communicate itself through appearances. Then you reach a point where these same people just don't see you anymore, which is something of a relief. Once again you become free to express your individuality because now you're doing it to please yourself, not some outside notion of what it is to be attractive or desirable. I have a thing for brightly painted toenails - they make me feel cheerful! - so I indulge myself constantly, and don't worry about whether my bright turquoise nails clash hideously with a pink shirt!! So even amidst the discomfort and feeling like an imposter [sic] in my own body, there is some good to come out of it! (Written story: 2)

Jane thus indicates that, by no longer feeling pressured by the imposition of impossible ideals, a whole range of new alternatives opens up. This supports my belief that those who have any hope of approximating the norm and, accordingly, face the constant struggle involved in attempting to be slim enough, fit enough, youthful and productive and attractive enough to feel acceptable, are in some ways in a worse position in some ways than those who, through being cast out of "normal" circles, come to recognise the fallacy inherent in the project of normalisation.

On a different level, a number of wheelchair users spoke or wrote about how they came to deal with people who patronised them. In commenting on this, Albert Robillard (1999) recalls how he learned to deal with readjusting his mind and his visual perceptions to his new spatial reality. A similar reorientation helped him adjust to people's negative attitudes.

The same thing happens with the underlying texts of utterances. With time, the statements of physicians, including specialists, and the "blame the patient" rhetoric of the nurses, asking me to "be a good boy," were transcended. I not only lived through these textual residues but the repetitive nature of the references made me realize that these statements and underlying texts were standard figures of speech. Pretty soon, Divina and I could recognize many of these figures, and we came to regard them with ironic glee ... We have gotten past the "be a good boy" form of speech, because we continue to resist this kind of patient management (47).

I have experienced a similar form of liberation through my academic work. By learning how entrenched these oppressive values are and how they tie in to the very foundations of
contemporary Western society, I am capable of letting go of the personal affront I used to experience. Karen talks about a similar shift of perspective which has left her feeling less disabled.

Karen: I think it has a lot to do with other people. It can make you or break you.

Me: Yeah, it's true, isn't it?

Karen: I think, basically, the biggest disability in the world is other people's attitudes.

Me: Oh yes, gosh.

Karen: They make the barriers.

Me: They do.

Karen: And once you've gotten over the part that having a disability isn't a problem, it's getting past those other people's attitudes, it doesn't really bother you anymore.

The same point is picked up in a conversation with Lesley.

Lesley: I never worry about other people's opinions. I think my opinions are far more important than anyone else's …

Me: And, so, did they have an effect on you before the disability?

Lesley: Oh yes, they did.

Me: Yes. So, this is another thing we can learn, another strength that we can develop because of this.

Lesley: Yes. So, if someone looked at me and sort of had an unpleasant look on their face, I'd think, what's wrong with me? But now I don't.

Me: [laughs]

Lesley: I think, what's wrong with them? What's their problem?

Me: [laughs]. It's a much more sensible way of looking at things, isn't it? And, it's a much safer way of looking at things too, isn't it? Much more comfortable.

Lesley: And I noticed that other people still have this reverence for other people's opinions.
This conversation was revolutionary for me. I had realised for a long time that other people's attitudes could only be disabling if I willingly took them on board. Still, letting go of the desire to please others seemed like a quantum leap that was impossible for me to take. Talking to Lesley made me realise just how foolish my preoccupations with other people's reactions, particularly strangers', actually were. Letting go of self-consciousness and shame allows one to move in the world with an identity that is more self-defined and constant. As president of the Christchurch branch of the Disabled People's Assembly, Lesley works for wide scale political change, while on another level she redefines herself and her perspectives so that the oppressive world view which exists towards disability does not encroach on her identity.

Nancy expressed the same refusal to take other people's reactions on board when asked about whether she had been hurt by other people's opinions. To this she replied:

Nancy: … really more indignant than hurt.

Me: Ah.

Nancy: Really, I think that my reaction...

Me: It's a better reaction. I'd prefer to be indignant than hurt.

Nancy: Yes, I don't think I've really been hurt because it's been so... it shouldn't have happened. That's all I can say, indignant rather than hurt.

Me: Well, that says a lot because being hurt means that perhaps it is then having an effect on your identity, whereas being indignant you are going, no, this is nothing to do with how I am and how I should be seen.

Nancy: That's right!

Me: And you are being indignant, so you are retaining your identity in that reaction.

Nancy: Yes, yes!

Once again I was incredibly inspired by this attitude. Like Lesley, Nancy refuses to be defined by other people's prejudices and retains a strong sense of self in the face of negative attitudes and behaviour. Rather than seeing others as mirrors which reflect back an image one can only
feel ashamed of, it is possible to see them as reflections of unfortunate social attitudes which need to be resisted.

**Personal Reflections and Change**

At this point I must admit that the first time I attempted to code for sexuality within the data and to write of sexual resistance, my own disabling self-prejudices curtailed my ability to see the liberatory potential which existed both within the data and within myself. At that point, I was drawing on Eli Clare’s (1999) arguments about developing subversive and empowering imagery. And even she recognised the difficulties inherent in healing the sense of rejection, failure and loss. Thus she writes:

> But how do I write about my body reclaimed, full of pride and pleasure? It is easy to say that abuse and ableism and homophobia stole my body away, broke my desire, removed me from my pleasure in the stones warm against my skin, the damp sponginess of moss growing on a rotten log, the taste of spring water dripping out of rock. Harder to express how that break becomes healed, a bone once fractured, now whole, but different from the bone never broken. And harder still to follow the path between the two. How do I mark this place where my body is no longer an empty house, desire whistling lonely through the cracks, but not yet a house fully lived in (Clare 1999: 32)?

In dealing with these issues, and in my attempt to come to terms with them, I wrote on 15 June 2003:

> I can only reach out across the abyss and clutch at half formed images and broken dreams. For, in my own life, I have made no momentous or even baby steps forward in resisting the disabling attitudes which overlay the experience of impaired sexuality and appearance. I may well recognise the faulty expectations that are tied to the oppressively narrow territory of the norm and I can claim to have made a shaky beginning in my newly empowered attempt to resist seeing myself in terms of other people’s negative attitudes. However, within the part of me that is most influenced by the kind of cultural imagery that leaves many of us feeling unsightly and undesirable and, thus, unlovable, my fragile core seems intent on eluding any of my attempts to politically reframe the position of my impaired body in social space. This vulnerable, very private centre of my “self” is most susceptible to the kind of crippling diffidence engendered by socially created expectations, while being, simultaneously, the least responsive to the promises of social change. For, no matter how strong I become as a political creature, my broken body exists as a concrete and indelible reminder of my deepest sources of fear and shame.

I now look back on those words from a space which allows me to experience a great deal more freedom and self-acceptance. This was partly the result of having read Shakespeare, Gillespie and Sells (1996) *The Sexual Politics of Disability: Untold Desires*. This involved an extensive
qualitative research project aimed at filling the void which had existed in both the conventional, heavily medicalised field of sexual rehabilitation and in disability studies itself, by setting out ‘to explore the emotional and sexual experiences of disabled people in a variety of key areas, relying predominantly on the verbatim accounts of disabled people themselves’ (1). What resulted was a collage of empowering stories which embody the personal experience of reclaiming a sexual identity as well as a critical theoretical framework in which to better understand them. Together, this combination of theory and practice serves to demonstrate that the social model can be extended to argue that ‘the barriers to sexual and emotional fulfilment do not reside in the impairments of the body but in the restrictions of our society’ (12). Many of the stories in Shakespeare et al.’s research resonated with subversive potential. They did this by challenging the gender stereotypes which constrain our choice of roles, sexual orientation and appearance; describing ways of thinking about and creating pleasure which exist outside of the expectations of conventional, heterosexual penetrative sex; and exemplifying much more effective ways of communicating needs, desires and preferences which fly in the face of the assumption that “good sex” is achieved through instinct and non-verbal cues.

Shortly after I read Shakespeare et al’s work, I became engrossed in two special issues of Sexuality and Disability (2000) (Volume 18, issues 3 & 4) which further strengthened my understanding of the nature of the “disabled identity” and the possibility of challenging the forces that produce it. Around the same time I began to read what I refer to in Chapter Ten as the “sexual rehabilitation texts”. While these texts were, in the main, heavily medicalised and based on individualistic prescriptions, scattered throughout them are certain emancipatory insights. For example, Bullard & Knight (1981) draw from a range of personal perspectives, both from disabled academics and research participants, which touch on issues of subversion and consciousness-raising.

The more I read about disability and sexuality from people who were not trapped in traditional normative prescriptions, the more inspired I became by the possibilities for change in both my research and my personal life. Based on these inspirations, I recalled three dialogues I had engaged in where the participants had spoken about changes to their sexual abilities and how they had responded to them. While these dialogues had only contained brief references, they suggested much in relation to the loosening of normative ties. Adrienne had said ‘Sure, the old ways of having sex were no longer an option ... But, use your imagination [pause] anything is possible’. When I had asked her later about this, she spoke about developing more pleasurable ways of engaging in sex with her partner, saying that ‘we both discovered ways of giving pleasure that we’d never have thought of if we’d stayed stuck in the patterns of, you know, quote, unquote, normal sex (personal email correspondence 11/2/04). And Neil, who was quoted earlier as saying that, initially, his impotence had resulted in him not being able to ‘feel like a real man anymore’, later mentioned that he had learned new ways of pleasuring his wife manually and orally with the consequence that ‘I see sex in a completely different way.’
In a conversation with Angus, the idea that sex is about performance rather than pleasure was beautifully articulated. Angus, who had earlier said that, ‘you see, I would run out of puff before I could reach orgasm and she, you know, began to feel inadequate because things weren’t in keeping with standard expectations’, explained later that:

Then one day, it was morning and we were in bed, just mucking around, not keen to get up, and I said to [Alice], “let me pleasure you”, and I could see that she really, finally got it … I could pleasure her and she could pleasure me and all the rest was so much window dressing.

Angus’ idea that sex is about pleasure rather than performance and that normative expectations can be dismissed as ‘so much window dressing’ is symbolic of the attitudes expressed by Adrienne and Neil and many of the others I have encountered in the literature, both conventional and openly political. All of them challenges oppressive notions of sex and sexuality. In the same way, Eli Clare (1999) calls for images ‘within disability communities and mainstream culture’ that are ‘honest, solid, shimmering, powerful, joyful images—of crip bodies and sexuality in the same way we need crip humor, crip pride, crip culture’ (117). Recalling poems like Marie Wade’s ‘A Night Alone’, Kenny Fries’ ‘Love Poem’, and P. H. Leay’s ‘The Hidden History of People with Disabilities’, Eli Clare says that:

With these images, I can begin to tunnel through my sense of being ugly and clumsy, unattractive and undesirable. When I look in the mirror, I can remember Joey on stage as a lover and a man with CP, his hands grasping, speech halting, in ways that look and sound familiar. I can see myself as sexy (117-119).

I feel the same way about the “images” and insights which have emerged through my research. They have enabled me to see that ways of thinking about sexuality and of being sexual exist outside of the mainstream and, as a consequence, I am shedding much of the self-consciousness and shame which encapsulated my formerly insurmountable sense of loss. Over the past year my illness and impairments have worsened in ways which have further limited my physical movement and changed my appearance. Yet, ultimately, the merging of these changes with my growing awareness of the possibilities inherent in escaping the norm have resulted in a dramatic increase in the level of intimacy, communication and sensual pleasure that I share with my partner and a weakening of the connection between how I look and how I feel about myself. How this shift of consciousness can help to challenge current forms of governance becomes apparent in the concluding section of this thesis.
PART FOUR

Governing Disability Through Technologies of the Self
Technologies of the self are meant to be performed by people who believe that doing so is an exercise in democratic freedom, but instead improves the ability of the people to be governed (Powers 2003: 233).

The narratives provide powerful examples of the ways in which identity can become either disabled or enabled in response to normalising pressures. Yet, to fully appreciate the processes of identity formation which crystallise through the disinterment of subjugated knowledges, it is necessary to undertake a further level of analysis which will place these notions of subjectification in their current political context. Whereas my genealogy of disability in Part Two provides the broad brushstrokes for understanding how impairment has come to result in the disabling of identity, and the narratives which frame Part Three fill in the finer detail of the lived experience of disability, my final layer of analysis offers the potential to link the macro- and the micro-sociological facets of this study by making sense of these stories and their historical context both in terms of the part they play in, and what they reveal about, our contemporary systems of rule. In this respect I draw on the insights offered by governmentality theorists.

Governmentality can be usefully understood as a historically specific genealogical tool. The sites of analysis favoured by governmentality theorists tend to involve the recent and ongoing transition from the so called “paternalism” of the welfare state to the economic rationalism and shrinking of the public sector inherent under neoliberalism. This juncture provides a particularly potent nexus through which to better understand contemporary processes of subjectification and their imbrication in the construction of disability as a governmental concept, that is, as a concept which functions to shape the way people think and act. By subjecting “work”, “independence” and “sexuality” to an analysis which will locate them within the diffuse networks of power which now serve to govern us ‘at a distance’, it becomes possible not only to understand how what appear to be the most intimate areas of our identities are continuously in process with governmental forms, but, as I have argued in Part Two in keeping with Foucault’s genealogical objectives, it can aid in our understanding of how we can and do manage to loosen our ties to negative self-perceptions.

As it was pointed out in Chapter One, governmentality studies traditionally steer well away from narrative sources and focus instead on textual material. Given that I am now about to focus the insights emerging from the narratives through a governmental lens, it is important that I briefly revisit the methodological issues which framed my decision to incorporate qualitative data in this kind of analysis. In this I draw inspiration from Stenson (1999) who argues against what he refers to as the ‘textual determinism’ inherent in governmentality studies (56). Stenson believes that, by focusing exclusively on texts, the governmentality approach risks retaining a ‘top down, even implicitly state-centred view of government’ which neglects to engage with ‘the messiness, tensions and ambiguities of everyday practices’ (op cit. 60, 59). He concludes by saying:

9 Please refer to pages 25-28 for a full description of governmentality as a concept and as an analytical tool.
In other words, under the auspices of [a] second model of governmentality, we need to go beyond a formal recognition of the great complexity of governmental techniques and accelerate the development and appropriation of a range of research tools, which will enable us to realize the rich research agenda which has been laid out. It is essential to supplement text-based analysis with this kind of empirical research, including ethnographic explorations of [those whose lives are] rarely filtered through the researcher-friendly medium of texts (Stenson 1999: 59).

When viewed from this perspective, the narratives which have been encapsulated in the last four chapters can be seen to provide a rich resource to mine alongside more traditional archival and discursive forms. I believe that the voices which were raised in the qualitative component provide clear demonstrations of the ways in which subjectivity is formed through the rationalities and technologies which currently shape our understanding of disability. And I also believe that, by presenting us with concrete examples of how people deal with the disabling of their identities by acting in ways which either serve to reinforce or subvert the norm, the narratives demonstrate innovative and illuminating responses to the reality that disability has been constructed as a pivotal counterpoint to the norm.

What is most illuminating in relation to the narratives, however, is the fact that the categories which emerged from the data coding process can be shown to be key sites of subjectification for people in general as opposed to issues which specifically affect those who become disabled. Accordingly, the following analyses into the ways in which disability and disabled subjectivity are currently being played out are based on the premise that work, independence and sexuality are being utilised as fundamental organising concepts in drawing the division between the affiliated and the marginalised in contemporary Western society. Recall Robert Murphy (1990), Marjorie Wagner (1986) and Glen’s statements [Part Three] in relation to how disabled people tend to be seen as either subverting or failing to achieve the norm.

It hardly needs saying that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish, however little most individuals may realize them (Murphy 1990: 117).

It is unpardonable in an individualist society to fail to be seen as self sufficient. Our society values a false sense of independence which results in pain and a sense of worthlessness for women and men whose capabilities have been ignored and whose potential has been uniformly underdeveloped (Wagner 1986: 97).

Glen: You know, you just want to be…….I don't like using this…….normal …and treated like they’d treat anyone.
The governmentality approach insists that words such as ‘youth’, ‘virility’, ‘activity’, ‘beauty’ and ‘independence’ need to be recontextualised in terms of what are now considered the essential qualities of the neoliberal citizen, those which define our current understandings of what is ‘normal’ (see Rose 1999; Dean 1999). Here the subject of government is constructed as active, enterprising, autonomous, self-reliant and capable of achieving and maintaining a level of fitness and physical attractiveness that will ensure sexual desirability. The winners in this process of normalisation are supposedly those who can most closely approximate these qualities and among the losers are those who remain passive, dependent and/or unattractive by normative standards.

What is pivotal to a governmentality reading of the mechanics of neoliberal subjectification is the understanding, firstly, that no one really ends up feeling like a winner because the impossibility of attaining the norm tends to keep even those who may appear successful feeling like they are falling short of these ideals (see Harris 1994), and, secondly, disabled people are no longer to be left untreated to serve as continual reminders of what not to be. Rather, they are increasingly being encouraged to develop the qualities of the active and enterprising neoliberal citizen so that they will no longer be “disabled” and it is this governmental process, one which purports to offer emancipation from a marginalised status, which will be explored in the remainder of Part Four.

To fully appreciate how this process of government operates, it is vital to understand that under the political rationalities associated with liberalism, whether in the form of welfare liberalism or neoliberalism, subjects are wherever possible to be governed through their “freedom”. Here Burchell (1996) points out that freedom needs to be understood, not as a ruse disguising the intentions of those in power, but as ‘a technical condition of rational government’ (24). According to this understanding, and in the current historical context, the enterprising and autonomous individual exercises choices which are mediated by expert knowledges and the market place. As Rose (1999) explains:

> the problem of freedom now comes to be understood in terms of the capacity of an autonomous individual to establish an identity through shaping a meaningful everyday life. Freedom is seen as autonomy, the capacity to realize one's desires in one's secular life, to fulfill one's potential through one's own endeavours, to determine the course of one's own existence through acts of choice (Rose 1999: 84).

Thus, it is freedom in this contemporary liberal sense which enjoins the individual, via a range of technologies, to the aspirations which are central to current political rationalities such as those which define the tenets of ideal neoliberal citizenship.

In the following two chapters I will seek to demonstrate that the two most salient technologies through which the processes of subjectification can be understood in relation to work,
independence and sexuality operate through welfare reform policy and the literature focused on sexual rehabilitation. I argue that both forms of intervention in the lives of disabled people can be seen to be ‘technologies of the self’ in that they have been devised to permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality (Foucault 1988m: 18).

As such, welfare reform can be seen to be aimed at facilitating the restoration of passive, dependent individuals who are “at risk of long term unemployment” to their roles as active citizens so that they can once again define themselves as occupationally engaged and self-reliant. Similarly, the sexual counselling and self-help literature intends to facilitate the development of improved body-esteem, sexual-esteem and sexual technique in accordance with the norms surrounding sexuality and appearance. Both appear to offer emancipatory potential and access to positive forms of identification which could ultimately lead to the disappearance of disability in its social model sense. However, as will become evident, these technologies have limited power to achieve what they promise because they largely remain tied to normative prescriptions and, thus, are more inclined to perpetuate the disabling of identity than to challenge it.
CHAPTER NINE

Welfare Reform as a Risk Management Strategy and Technology of the Self

The narratives outlined in Part Three indicate that people who develop impairments tend to experience their losses of independence and occupational status as key factors in the disabling of their identities. I contend that, in the contemporary context, the fundamental role that work and independence have come to play in the process of identity formation in general and, more specifically, in relation to the disabling of identity, can be best understood by analysing their immersion in current welfare reform policy and disability rights arguments. It can be shown that welfare reform and disability rights share an agenda which is based on the belief that increased access to employment is the fundamental unit of social change required to ensure that people with impairments regain their independence and are no longer disabled by their lack of access to social resources. It is my intention to problematise the logics upon which these frameworks for social change are constructed so as to bring to the surface the effects they have on the constitution of the neoliberal subject and the experience of disability in contemporary times.

To achieve these ends, I begin by exploring the context in which welfare reform is being developed. I argue that the perceived need to reform welfare systems in the first instance is based on shifting notions of the shape the ideal subject of government should take and that these are best understood when viewed against the backdrop painted by the withdrawal of the welfare state and the reconfiguration of citizenship in terms of risk. I then draw on current Australian welfare reform policy documentation to show how the redefinition of disabled people as “job seekers” who are “at risk of long-term employment”, although it ostensibly promises the means through which to regain a positive identity in terms of independence and employment, contributes to their further marginalisation. Finally, I show that, by remaining trapped in the same value system which prioritises work and independence, the disability rights movement weakens its ability to contest the individualistic premises of welfare reform and, in an attempt to address these limitations, I draw on the narratives and certain challenges which are developing in response to the normative features of disability theory.

Disabled by Dependency and Protection from Risk

Under the earlier form of the welfare state, people excluded from employment because of disability were offered assistance in the form of varying degrees and styles of income support and social services (OECD 2003a, b). These systems of welfare support have tended to operate within a paternalistic framework of state sponsorship which, by way of the direct interventions of such experts as doctors, social workers and rehabilitation professionals, provided “guidance” and ongoing assessment. Since the early 1980s, however, these systems
have increasingly come under attack because, it is claimed, they produce a form of dependency and passivity which is self-perpetuating and highly damaging to the life chances of welfare recipients. Rose (1996b) touches on this transition in the following description of the subject of welfare reform as construed by neoliberalism.

> They are people whose self-responsibility and self-fulfilling aspirations have been deformed by the dependency culture, whose efforts at self-advancement have been frustrated for so long that they suffer from "learned helplessness", whose self esteem has been destroyed. And, it thus follows, that they are to be assisted not through the ministrations of solicitous experts proffering support and benefit cheques, but through their engagement in a whole array of programmes for their ethical reconstruction as active citizens — training to equip them with the skills of self-promotion, counselling to restore their sense of self-worth and self-esteem, programmes of empowerment to enable them to assume their rightful place as the self-actualizing and demanding subjects of an "advanced" liberal democracy (59-60).

Thus, welfare programmes are no longer to be aimed at maintaining a static system of income support and assistive services, the hallmark of the welfare state. They are instead to be focused upon facilitating what Rose refers to as the ‘ethical transformation’ of its subjects into ‘active citizens’, a transformation which has at its primary objective the redefinition of disabled people in terms of their ‘work capacity’, ‘job readiness’ and ‘self-reliance’.10

This shift in perspective has been shaped in accordance with an increasingly potent rationality of government, that which is tied to notions of “risk”. In his seminal treatise, Risk Society, Beck (1992) argues that:

> In advanced modernity the social production of wealth is systematically accompanied by the social production of risks. Accordingly, the problems and conflicts relating to distribution in a society of scarcity overlap with the problems and conflicts that arise from the production, definition, and distribution of techno-scientifically produced risks (19).

As such, Beck (1992), and others like Giddens (1994), view “risk society” as a reality which has been brought about by contemporary social and economic forces. Giddens characterises (and criticises) the traditional welfare state on the basis that ‘[t]he more it tried to guarantee security and minimize risk, the more it fostered dependency and established new risks - risks that were perceived as both the product of its own inefficiencies and its entrapment of its subjects’ (Pratt 1999: 14). Conversely, an analytics of governmentality proposes that risk is simply a way of seeing things which, as Dean (1999) argues, ‘render[s] reality in such a form as to make it amenable to types of action and intervention’ (178). And, when applied to income support programmes, the notion of risk can be seen to provide the rationale which underpins the perceived imperative to reform systems of welfare provision.
Higgs (1998) points out that sociological understandings of risk, such as those mapped out by Giddens and Beck, support the belief that, by ‘accepting the challenges offered by risk and reflexive modernization’ and ‘abandoning some of the securities of the past’ such as those offered through welfarism, the neoliberal subject becomes empowered to pursue market driven pathways to success (179). Giddens (1994) describes this subject of government as ‘the autotelic self’:

Schemes of positive welfare … would be directed to fostering the autotelic self. The autotelic self is one with an inner confidence which comes from self respect, and one where a sense of ontological security originating in basic trust, allows for the positive appreciation of social difference. It refers to a person able to translate potential threats into rewarding challenges, someone who is able to turn entropy into a consistent flow of experience. The autotelic self does not seek to neutralise risk or to suppose that ‘someone else will take care of the problem’; risk is confronted as the active challenge which generates self-actualisation (192).

The autotelic self is the ideal neoliberal citizen who embraces risk. When defined against the autotelic self, the subject of welfare, by having been ‘shielded from risk’, is viewed, as Rose describes above, as ‘deformed by dependency culture’ and, thus, ripe for rehabilitation or, in neoliberal terms, self-actualisation, in the drive to achieve full neoliberal status.

However, according to a governmentality perspective, welfare reform is not to be understood as a response to an increase in the actual number and intensity of risks. Rather, it is a reconfiguration of dependency and employment status in terms of an ever shifting alchemy of risk management strategies. While the welfare state operated through the technology of social insurance which served to collectivise risk, the retraction of welfare support associated with neoliberalism can be understood to have resulted from what O’Malley (1996) has coined as the development of the concept of ‘prudentialism’. He explains that prudentialism is a technology of governance that removes the key conception of regulating individuals by collectivist risk management, and throws back upon the individual the responsibility for managing risk. This is advocated by its supporters as “efficient”, for individuals will be driven to greater exertion and enterprise by the need to insure against adverse circumstances - and the more enterprising they are, the better the safety net they can construct (197).

Accordingly, people who have been assessed as “disabled” and, therefore, eligible for income support are currently being redefined as “at risk of long-term unemployment”. This is a shift which, while it acknowledges the historical relationship which exists between the concepts of

10 These terms are used in the Australian welfare reform documentation which will be explored in the following section.
“work” and “disability”, essentially aims to reduce disabled people’s access to a level of income support which is higher than that received by unemployed people while increasing the points at which surveillance and guidance are applied to their lives.

Thus, as Lupton (1999) argues, “[t]he designation of the label “at risk” often serves to reinforce the marginalized or powerless status of individuals’ (113). In the case of disabled people, this potential for further marginalisation is associated not only with a reduction in access to special benefits by way of reclassifying disabled people as simply “unemployed”, but it rests, more fundamentally, on the development of a new benchmark in relation to “active citizenship”. Under the increasingly persistent demands of the notion of enterprising subjectivity, those who fail to achieve independence through employment will be accused of lacking the qualities necessary for self-actualisation. As O’Malley (1996) argues, the unemployed have a responsibility to upgrade their skills, self-esteem and marketability and, if they do not succeed and continue ‘to rely on the state to deal with the harmful effects of known, calculable and individually manageable risks’, they can only be perceived as ‘feckless and culpable’ (202).

As a consequence of neoliberalism’s basic premise that emancipation stems from change at the level of the individual, welfare reform as a risk management strategy exists in tension between two opposing modes of subjectification. One appears to offer the potential to aid in the reconfiguration of the disabled identity in more positive, empowering terms, while the other threatens to impose an even less desirable identity due to the effects of poverty and victim blaming which logically follow from prudentialism’s focus on individual responsibility rather than social change. This tension can be effectively foregrounded and clarified by exploring the linguistic foundations of current Australian welfare reform policy and its relationship to the liberatory language of the disability rights movement. By analysing the terminology which is currently being devised to redefine disability, disabled people and their proposed modes of emancipatory action, it becomes possible to untangle what remains normalising and, as such, oppressive, and what may properly enable subversion.

The Appropriation of Liberatory Language within Australian Welfare Reform Policy

Australian welfare reform policy, as it is currently being promoted by the Commonwealth Department of Family and Community Services (FaCS) and outlined in the McClure Reports (FaCS 2000a, b) and Australians Working Together (FaCS 2002a), would appear, on the surface, to offer disabled people the potential to achieve the state of full social participation and independence that is at the heart of the disability rights agenda. Indeed, if, as both welfare reformers and disability activists argue, “disability” is understood, not as a medical or physical problem, but as a state of social exclusion caused by lack of access to employment and social resources, then the removal of these barriers to inclusion should theoretically be capable of making “disability” disappear. I argue that this apparent confluence of positions between
government and proponents of the social model has eventuated, firstly, because the Government has been able to reappropriate facets of the liberatory language that has framed the disability rights movement for the past three decades, and, secondly, because the disability rights movement has embedded some of its major objectives in the same framework of meaning and value which underpin the kind of libertarian policies which will ultimately undermine them.

From the landmark speech delivered by the then Minister for Family and Community Services, Jocelyn Newman (1999a), to the present time where welfare reform is being articulated through *Australians Working Together* (FaCS 2002a) and the 2002-2003 Federal Budget’s ‘Recognising and improving the work capacity of people with a disability’ (FaCS 2002b), language which has been pivotal to the articulation of the aims of the disability rights movement has been utilised in such a way as to suggest that the proposed changes to the welfare system are entirely consistent with emancipatory objectives. Consider, for example, the following statement which outlines the fundamental principles of the Commonwealth Disability Strategy.

> The Government's vision for Australia is a society where all Australian's can live, work and participate fully in community life. Nearly one in five Australian have a disability and the Government is committed to widening their opportunities for *independence, access* and *participation* (italics mine) (FaCS 2000c: 2).

The terms “independence”, “access”, and “participation” represent concepts which are pivotal to the disability rights agenda. When, for example, the Union of the Physically Impaired Against Segregation (UPIAS) launched the social model in Britain in 1976, it based its arguments on the premise that people with impairments had been disabled by 'help which essentially entrenches our dependence on the state instead of encouraging our independence and active participation in the mainstream of life’ (italics added) (as cited in Oliver 1996: p. 25). The language and concepts it employed thus appear to be reproduced in the fundamental principles of welfare reform in Australia. I will show, however, that a closer appraisal of the concepts in which these terms are embedded reveals vastly different agendas. In this respect, I return to the insights developed in Chapter Three where it was argued that surface meanings which often appear to mirror “reality” are always immersed in particular conceptual landscapes which determine the “truths” they purport to represent. In relation to an analytics of governmentality, Rose (1999) argues:

> It is possible to govern only within a certain regime of intelligibility - to govern is to act under a certain description. Language is not secondary to government; it is constitutive of it. Language not only makes acts of government describable; it also makes them possible (28)

To point to differing conceptual frameworks in relation to welfare reform and disability rights is not to claim that they are not largely constructed from within the same ‘regime of intelligibility’.
Neoliberal ideals are extremely pervasive and are as integral to the desires and aspirations of the governed as they are to the frameworks of government. However, what is at variance here is a rudimentary conflict between the individualistic view which currently drives welfare reform and rests on the belief that it is the individual who is responsible for change and the social model view which prioritises change at the level of society, a view which, although it has some points of overlap with neoliberal ideals, is fundamentally at odds with the rhetoric of prudentialism. In the following section I suggest that an analysis of each party's use of the term “access” and its relationship to the concepts of “independence” and “participation” provides a particularly effective means for pinpointing the nature of this discursive dissonance and the way it ultimately affects the kinds of subjective locations which are available to disabled people.

“Access” as Inclusive Versus “Access” as Exclusionary

If “independence” is the primary goal of the disability rights movement, a goal that both relies upon and facilitates participation, then “access” emerges as one of the principal means for achieving it. In keeping with welfare reform policy, the disability rights movement agrees that access and employment are intimately linked, as access to employment and access through employment are vital components in the quest for independence. As Russell (1998) points out: ‘Activists contend that disability oppression is about discrimination and lack of access. Since society grants status based on work, being able to work is a way to move beyond dehumanization’ (81). Under this view, the removal of the barriers which prevent people with impairments from accessing social resources including employment is seen to necessitate a range of structural changes, such as, adaptations to the built environment to increase physical access to public spaces, the enactment of anti-discrimination legislation to increase access to employment, better access to goods and services which can contribute to independence, and the contestation of attitudes and cultural imagery which devalue disabled people so that they can access more positive identities.

The concept of “access” as it has been woven throughout current welfare reform documentation, however, means something entirely different. In very much the same way that words such as ‘joycamps’ functioned as euphemisms for forced labour camps in Orwell’s (1948) Newspeak, so the use of the word “access” by policy makers functions in a deceptive manner to conceal intentions which are in direct contradiction to “access” as it is promoted by the disability rights movement. The Australian Government claims that disabled people’s lack of access to employment is the result of an income support system which is too ‘generous’ and which serves to ‘reduce labour market attachment’ (FaCS 2000a: 34, 39). This argument has culminated in the decision to redefine disabled people as those ‘at risk of long-term unemployment’ and, as a consequence, to shift large numbers of them from the Disability Support Pension (DSP) to Newstart (an equally Orwellian euphemism for unemployment benefits), where they will supposedly have greater access to the labour market (FaCS 2002b).
Before exploring these changes to the DSP in more detail, it is pertinent to discuss the pivotal role played by access within the current neoliberal rationale. As in the case of disability rights, “access” is being viewed as the answer to social problems deriving from its inverse, “exclusion”. Yet, as Rose (1999) points out, this entails the logics of individual responsibility rather than those which would contribute to social change.

Social problems are recast as ‘the problem of the excluded’. The unemployed are understood as those excluded from regular work. Poverty is understood as exclusion from the resources and benefits necessary to participate as a full citizen in the life of the community. And these various forms of exclusion are to be counteracted by strategies of inclusion, for example an ‘intelligent welfare state’ which gives ‘a hand up not a hand out’, active labour market policies involving training and job search, even, in the words of the current leader of the Labour Party, enfolding and embracing all in a ‘stakeholder economy’ (258).

In this context, “access” or “inclusion” is believed to be achievable via the provision of expert guidance and training aimed at assisting disabled people to become self-actualising subjects who are capable of competing in the employment market as it stands. When understood in this way, access requires the removal of the safety net of special forms of income support, but disconnects itself from the perceived need to change the social structures which have excluded disabled people from full economic and social participation in the first place. Hence, the prime mode of increasing “access” for disabled people comes to rely on the removal of the more generous system of benefits and income support currently offered to compensate for the additional costs of disability. It is now believed that, by being sheltered from the risks inherent in an employment environment which is increasingly being structured around short term and/or part-time jobs, disabled people have been given too many incentives to remain unemployed. Consider Senator Newman’s (1999b) original arguments in relation to incentives.

Disability Support Pension is paid at a higher rate than Newstart Allowance, it has more generous income and assets tests than some other payments, it is not activity-tested, it is not taxable and it gives people access to the Pensioner Concession Card (17).

Following this, first in the McClure Reports (FaCS 2000a: 35; FaCS 2000b: 19) and then in the policy developments which followed, it has been claimed that ‘better conditions for pensions create incentives for people to go on pensions rather than allowances, and reduces their focus on seeking paid work’ and that this results in some people ‘downplaying their abilities’ (FaCS 2002c: 13). Evident here is the form of economic rationalism whereby benefit reductions are justified on the grounds that overgenerous benefits encourage rort, deception and passivity. This logic, however, is overlaid by a different discourse which justifies reform in the name of increased access and improved opportunities. Hence, while one part of government discourse
is steeped in individualism and economic rationalism, another speaks in terms of empowerment and social justice.\textsuperscript{11}

This vacillation between empowerment and coercion encourages the Australian public to engage in Orwellian “doublethink”, the ability to hold two completely contradictory beliefs in one’s mind simultaneously and accept both of them. And one of the reasons why this kind of contradiction remains below the level of consciousness is because, as Rose (1999) argues, freedom and coercion enjoy an intimate connection within neoliberalism.

\begin{quote}
[T]he programmatic and strategic deployment of coercion, whether it be in the name of crime control or the administration of welfare benefits, has been reshaped upon the ground of freedom, so that particular kinds of justification have to be provided for such practices. These might include, for example, the argument that the constraint of the few is a condition for the freedom of the many, that limited coercion is necessary to shape or reform pathological individuals so that they are willing and able to accept the rights and responsibilities of freedom, or that coercion is required to eliminate dependency and enforce the autonomy of the will that is the necessary counterpart of freedom (10).
\end{quote}

Accordingly, the need for coercion is being defended through the argument that ‘some people lack confidence in their own capacities or the motivation to test their prospects for themselves, while a small group may even view income support as an unconditional right’ (FaCS 2000a: 57). Hence, some people will require ‘persuasion’ and ‘encouragement’ and ‘the most resistant group may need to be compelled to consider and ultimately to undertake a course of activity that might lead towards greater self-reliance’ (FaCS 2000a: 57). Occasionally, it is envisaged that ‘complete withdrawal of income support [will be required] as the last resort where people have the capacity to participate and where there is no reasonable basis for non-compliance’ (ibid).

Those people being shifted from the DSP to Newstart because it ‘will link these customers to suitable interventions or services … to improve their capacity to work’ (FaCS 2002b) may face serious disadvantages given that any expression of doubt in relation to their level of ‘work capacity’ may result in them being viewed as ‘non-compliant’, ‘unmotivated’, ‘resistant’ or, even worse, as holding the view that ‘income support is an unconditional right’ (FaCS 2000a: 57).

In making the argument that coercive measures such as these will result in the kind of increased access that disabled people actually seek, government discourse draws liberally on the spatial metaphors which are employed in disability discourse. It is argued, for example, that welfare reform seeks to ‘break down’ the ‘rigid boundaries’ which have ‘constrained [disabled people’s] access’ to employment (FaCS 2000a: 24, 25). In practice this will be achieved,

\textsuperscript{11} Australian welfare reform policy is focused upon here as it provides a strong example of the trends which are common across liberal democratic nations. In a similar vein, Bill Clinton (1992), for example, announced his aim to ‘end welfare as we know it’ (O’Connor 2001: 5) prior to the enactment of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 and current British Prime Minister, Tony Blair, signalled the end of what he refers to as the ‘something-for-nothing welfare state’ when he proposed cuts of £1.2 billion a year from the disability benefits programme (Lyall, 1999: 3).
beginning in March 2004, with the introduction of a new assessment procedure which is being described as a ‘gateway’ through which access will be gained to ‘better outcomes for the individual in terms of participation in the community and employment’ (FaCS 2000b: 13). In reality, this gateway will lead to reduced access to the more generous income support category represented by the DSP without any associated job creation schemes or labour market adjustment. Under the new scheme, growing numbers of professionals and agencies will be called upon to intervene in the lives of disabled citizens. The role of doctors, who have long been drawn upon to act as ‘gatekeepers for disability benefits’ (Hickel 2001: 237), will be supplemented by the calculations of ‘work capacity assessors’ and ‘psychologists’ who will decide who should be moved from the DSP to Newstart. This increase in the range and intensity of professional scrutiny follows from the upgrading of disabled people to a “high risk” category, whereby attempts to enhance the “freedom” of problematic subjects actually increases the points at which surveillance and coercion are likely to occur (Ericson & Haggerty 1999). As Rose (1999) argues:

a whole array of control agencies … become, at least in part, connected up with one another in circuits of surveillance and communication designed to minimize the riskiness of the most risky. They form a multiplicity of points for the collection, inscription, accumulation and distribution of information relevant to the management of risk … The logics of risk inescapably locate the careers and identities of such tainted citizens within a regime of surveillance which actually constitutes them all as actually or potentially 'risky' individuals (260).

The conviction that an array of behavioural specialists - psychologists, counsellors, educators and work capacity assessors - are needed to energise subjects and effect welfare reform harks back to the assumption that lack of motivation lies behind the “failure” of disabled people to find employment. This assumption remains deeply pervasive even though its premises have been seriously undermined by a recent study commissioned by the Department of Family and Community Services itself. This study, which evaluated an extensive trial of the proposed assessment process, the Assessment and Contestability Trial (FaCS 2003d), revealed that the interventions employed, such as vocational guidance, training, rehabilitation and job search support, had ‘no significant effect on job search, volunteer work or the proportion of individuals in employment’ (Bruenig et al. 2003: 97). Moreover, an associated finding by the ABS demonstrated that 97.1% of disabled people who had been actively seeking work were still unemployed a year later (cited by Argyrous 2003: 4). It is interesting, then, that the notion that unemployment can be solved by way of behavioural interventions remains integral to the development of current welfare reform strategies.

What, then, does government offer disabled people in terms of job opportunities? The question is particularly pertinent in a period characterised by ‘a hostile labour market’ (McClelland 2002:}
218) where ‘there are still seven applicants out there for every job vacancy’ (Silkstone 2003: 8). True to its neoliberal foundations, welfare reform does not subscribe to job creation schemes and, in Australia, relies on an alternative mode of participation in the form of unpaid work. In a recently drafted handout aimed at DSP recipients it is suggested that ‘by doing Community Work you can benefit by gaining valuable skills and experience while giving something back to your community’ (FaCS 2003c: 1). A parallel argument is that engaging in volunteer work can be thought of as a ‘strategy to develop [one’s] capacity for economic participation’ (FaCS 2000b: 4). Indeed, each of the case studies developed in the Interim McClure Report (FaCS 2000a) to demonstrate how the new system would operate involved hypothetical instances of people who would ultimately regain a position in the workforce by initially volunteering their services for free (such as Hans who donned a back brace at age fifty and, after offering his services for free to an internet service provider for six months, obtained paid work). A particularly interesting facet of this enterprise is that the majority of voluntary work exists in the welfare sector so that, what Saunders (2002: 244) refers to as ‘“welfare work” being performed by “welfare recipients”’ may end up serving both as a form of ‘workfare’ similar to Work for the Dole (O’Connor 2001) and a solution to the shrinking state welfare sector. This novel solution not only privileges privatisation, economic rationalism and self-reliance, but, as far as the authorities are concerned, will contribute to the ‘self-esteem’ and ‘psychological health’ of those who participate in this way (FaCS 2000b: 3).

Apart from the poverty which will directly result from the proposed changes to the pension system, there are more subtle processes at play. In the absence of the structural reforms which would help to ensure that employment was indeed accessible to people whose impairments do not necessarily prevent them from working, the loss of the title of “disabled” will mean that disabled people will be consigned an identity which is even more oppressive than that held previously. Once seen as lacking the qualities of citizenship due to misfortune, disabled people will now be in the most precarious position of an ever increasing number of long-term unemployed, a group which is believed to comprise only those who fail to adequately respond to the challenges and opportunities inherent in contemporary “risk society”. In sum, welfare reform reconfigures disability as personal responsibility rather than a social imposition, a sleight of hand that leaves ‘disadvantaged job seekers’ with impairments with less means than ever for accessing or challenging normative identifications.

**Problematising the Imperative to Work and Be Independent**

So far I have argued that welfare reform policy has appropriated certain disability rights language and concepts in its quest to justify both immediate cost-cutting and the longer term neoliberal agendas of privatisation and labour market flexibility. I now suggest that this has not occurred without some level of complicity, albeit largely unintentional, by those who seek to defend the interests of disabled people. One of the main reasons why the two camps appear to
share a similar agenda is that both embed their arguments in the same paradigm or ‘frame’ and, therefore, tend to share ‘a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation’ (Entman 1993: 75). Consequently, in Marks’ (1999) view, ‘the social model’ weakens its position by ‘adopting many of the values of capitalist society by prioritising work and independence’ (88).

Bagenstos (2003) points out that activists have often found it expedient to adopt the dominant rationale and cloak their arguments for increased access in terms of the savings it will bring and the self-reliance it will promote. Hence, disability theorists and disability rights leaders often speak in a distinctly neoliberal manner. Thus, for example, we have suggestions that ‘a national disability income might itself be exclusionary’ (Oliver & Barnes 1998); that the move ‘from a welfare mentality to one that has seen [disabled people] become contributing, productive members of society’ is to be applauded (Roberts 1989: 239); and that income support encourages ‘childlike dependency’ and is ‘tantamount to denying the disabled both their right to participate in the life of the community and their right to full personhood’ (De Jong 1983: 18). All of these authors, while intending to speak on behalf of disabled people, appropriate neoliberal concepts and, as such, contribute to the myth that current welfare reform is emancipatory in nature.

At an underlying level there are certain, seemingly immutable concepts that both government and disability proponents actually do share, concepts which are distinctly problematic in relation to issues of equality and access. These include the belief that, if the barriers to employment were removed, all people with functional limitations would be able to engage in paid work. Associated with this belief is the notion that employment is fundamental to a positive identity, the ability to be independent and the right to claim citizenship. The problems symbolised by this view are twofold. Firstly, due to the rapid rise in unemployment in response to the globalisation of labour, the effects of technological innovation and the shrinking of the public sector as an employer, there are not enough jobs to go around, and, secondly, some people simply cannot work because of the nature of their illnesses or impairments (Gallagher 1993).

Abberley (1999) argues, alternatively, that ‘just because the main mechanism of our oppression is our exclusion from social production, we should be wary of drawing the conclusion that overcoming this oppression should involve our wholesale inclusion in it’ (12). He, along with a growing number of disability theorists (such as Gallagher 1993; Hillyer 1993; Marks 1999), believes that, even if anti-discrimination policies were successful in creating more employment opportunities for a proportion of the disabled population - something which is certainly not being facilitated by welfare reform policy - this could ‘have the effect of maintaining and perhaps intensifying its exclusion of the remainder’ (ibid). He goes on to argue that a truly liberatory theory of disability would require the rejection of ‘work as crucially definitional of social membership’ and, instead, ‘the posing of values counter to the classical conservatives and
radical consensus, the assertion of the rights of the human “being” against the universalisation of human “doing” (13). And, in conclusion, he reiterates ‘that full integration of impaired people in social production can never constitute the future to which all disabled people can aspire’ (ibid).

This recalls the views of those participants who, as discussed in Chapter Seven, learned to let go of the imperative to work. Hunt’s (1966: 218-9) discussion is particularly important here. He writes of disabled people being able to ‘contribute in less obvious ways; even, and perhaps especially, if these seem insignificant beside the “real world of work” ‘ and suggests that ‘[o]ur freedom from the competitive trappings that accompany work in our society may give us the opportunity to demonstrate its essential elements’ and, as such, that ‘we can act as a symbol for the pre-eminent claims of non-utilitarian values, a visible challenge to anyone who treats his job as a final end itself’ (Hunt 1966: 218). He also argues that if and when our physical conditions become so severely compromised that we can “do” nothing, we can demonstrate that being ‘passive’, far from being seen in terms of failure, is ‘one half of the human reality.’ After all, he argues, ‘[t]hose who lead active lives are perhaps especially inclined to ignore man’s need to accept passivity in relation to so many forces beyond his control’ (Hunt 1966: 218-219). Although Paul Hunt wrote these words almost forty years ago when neoliberalism was still relatively dormant, they present a strong argument against the tenets of individual responsibility and the belief that we have the power to control our circumstances and become active citizens no matter what.

Hunt thus suggests that the condition of “disability” has the potential to teach valuable lessons to all people in relation to the constraints and misconceptions perpetuated by the normative view. The insights which the participants in this study raised in relation to “independence” have the same kind of effect. Whereas welfare reform policy equates independence with the capacity to stand alone financially and uses the word interchangeably with “self-reliance” or the capacity to do things without help (see FaCS 2000a, b; FaCS 2002a, b, c, d), many of the participants in this study, alongside a number of disability theorists, redefine independence in terms of inter-dependence and an understanding of autonomy as the right to make choices and to have equal access to social resources (Reindal 1999; Bricher 2000). In this way, independence as a state of complete self-reliance is exposed as a myth, the reality being that we are all dependent on one another and on a variety of existing structures for access to resources and meaningful lives (Davis 1998; Barnes 1999).

When framed within a rationality which glorifies the ability to be self-reliant, the need for help can only be seen as unpalatable (Penning 2002) and it is commonly felt that people who do have to rely on others lack initiative and are somehow morally inferior (Bryan 2001: 324). This is why people who have such support needs so often feel ashamed, particularly, as was apparent in the narratives, if the fulfilment of these needs is seen in terms of "burden" and "self-sacrifice".
In this study, this was brought into high relief at the point where it became apparent that there was a distinct division between those who had access to paid personal assistants and those who relied on the goodwill of friends and family. It is significant that the three New Zealand women who served to most clearly exemplify the benefits of access to formal care could be said to be among the most functionally impaired people in the sample. Yet, their attitudes and lifestyles demonstrate a high degree of emancipation, such that they appear to be, in effect, less disabled, in a social model sense, than many of those whose impairments are greater. I have argued that this is because those who are forced to rely on informal support structures are in effect disabled by the shame and irrevocable gratitude that is linked to this form of dependence.

It can thus be argued that feelings of shame serve to immobilise disabled people to a far greater degree than any of their physical restrictions because it often makes them afraid to ask for help and to feel demoralised when they do. In Wade’s (1994: 89) words it is often the hidden, unstated reason why ‘millions of us don’t get out of bed or get by with inadequate personal care. Because we don't want to say this need that shames us out loud …’. To remedy this shame and the limitations, both structural and self-initiated, that it invokes, it is vital to politicise it by challenging the rationales which conflate independence with self-reliance. As Eli Clare (1999) was quoted as saying in Chapter Six: ‘Independent living advocates measure independence not by how many tasks one can do without assistance, but by how much control a disabled person has over his/her life and by the quality of that life’ (89). This recognition that independence necessitates autonomy, not self-reliance, and that autonomy represents the capacity to make choices, is a vital ingredient in any effective movement for reform (Barnes 1992).

In drawing out the connections between the concepts of “work” and “independence” and the identities of those who are disabled by them, I am not claiming that neoliberalism bears a singular responsibility for imposing marginalised identities on people with impairments because of their dissociation from the employment market and their need for assistance. As the genealogy outlined in Part Two demonstrates, these concepts have been pivotal to the construction of “disability” over the past three centuries. However, what I do argue is that the rationality of neoliberalism overarches a whole new way of problematising disability and, as such, of affecting the processes which govern subjectification by way of the contemporary conceptualisation of work and independence. As a risk management strategy and a technology of the self, welfare reform policy is a particularly powerful mechanism for reinforcing the prescriptions of the norm. And what results is that those who fall short of its precepts either feel stigmatised and inadequate because they remain defined by normative principles or they ultimately develop the resources to subvert the norm and, in this way, become capable of achieving a more liberated view of themselves than those who are able-bodied and not as inclined to recognise the operations and costs of the hegemonic norm.
CHAPTER TEN

Constructing the Self in Relation to Sexuality

The impact on identity at the site of sexual subjectification can also result in self-perceptions which are either limited by normative prescriptions or liberated by the recognition that these normalising boundaries are not immutable. Indeed, sexuality can be shown to be an even more pivotal site of identity construction and reality configuration than either work or independence. As Hayden (2001) argues when drawing from Foucault’s *History of Sexuality*, ‘sexuality discourse is a primary site through which power operates; it is one of the means through which both individuals and populations are controlled, “normalized,” and “disciplinary” ’ (30). Therefore, an analysis of the discourses which are currently being developed to govern the sexuality of disabled people can be expected to shed new light on why the narratives surrounding sexuality suggest that it may be the most difficult realm of identity loss to challenge and, indeed, to further illuminate the nature of contemporary subjectification in general.

I begin by furnishing the historical and analytical background necessary for the exploration of the government of disabled people through their sexuality in contemporary times. I will then argue that the sexual rehabilitation literature operates, like welfare reform, as a powerful technology of the self by facilitating the development of pathways of identity formation which link individual subjectivity to systems of power by way of expert knowledges. As with all technologies which are developed within the rationality of neoliberalism, sexual rehabilitation is based on the belief that individuals are capable of, and are indeed responsible for, making the necessary changes to enhance their personal freedom and choice. As such, although on many levels the technology of sexual rehabilitation can be seen to contain the seeds of emancipation, it falls short of its goals because it is essentially paternalistic, tends to reproduce normative values and places the onus on the individual without being critical of the social environment in which disability is created.

The History of Sexuality in Relation to Disability

As I sought to demonstrate in Part Two, a genealogical analysis, instead of assuming the self-evident nature of the concept under investigation, traces its emergence and development as a product of particular vested interests over time. When sexuality is viewed through this Foucaultian lens, it becomes apparent that it is not, as conventional histories would suggest, an innate human quality which was repressed by Victorian values and liberated by those who challenged this repression. Instead it appears as:

an especially dense transfer point for relations of power: between men and women, young people and old people, parents and offspring, teachers and students, priests and laity, an administration and a population (Foucault 1978: 103).
Part of sexuality’s ability to be ‘an especially dense transfer point for relations of power’ lies in its deceptive capacity to appear natural. Hence one of my research participants, Adrienne, exclaimed: ‘Being a feminist I believe in the adage - the personal is political. But sexuality? It just doesn’t fit … I can’t think of anything more personal and less political.’

This belief in the “natural” character of sexual relations underpins the nature/repression hypothesis criticised by Foucault. The main danger Foucault sees in accepting ‘the repressive hypothesis’ - and this is particularly pertinent in relation to the conventional views which many disabled people hold about their sexuality - is that, while challenging sexual repression and claiming a sexual identity may well appear to be an emancipatory act, it can actually constitute an even deeper immersion in the effects of power and, thus, reduce rather than increase one’s sexual agency. This does not mean that there are no avenues of resistance available to those whose sexual identities and access to loving relationships have in fact been disabled by oppressive practices. On the contrary, an understanding of how power produces subjectivity provides the very means for opening up new ways of thinking and being. As Simon (1995) has already been quoted as saying, ‘genealogy exposes the contingency of what appears natural, enabling one to loosen the ties to one's identity’ (109).

In challenging the notion that sexuality has been continuously prohibited and silenced, Foucault (1978) argues that the last three centuries have represented ‘a veritable discursive explosion’ in relation to sex (17) and describes his overall project as follows.

What is at issue, briefly, is the overall “discursive fact” the way in which sex is “put into discourse.” Hence, too, my main concern will be to locate the forms of power, the channels it takes, and the discourses it permeates in order to reach the most tenuous and individual modes of behavior, the paths that give it access to the rare or scarcely perceivable forms of desire, how it penetrates and controls everyday pleasure - all this entailing effects that may be those of refusal, blockage, and invalidation, but also incitement and intensification: in short, the “polymorphous techniques of power” (11).

In essence, Foucault suggest that the individual discourse of confession that emerged in the middle ages - which, he argues, linked the ‘moral theory of concupiscence’ to the sovereign power of church and state - was gradually but inexorably ‘broken apart, scattered, and multiplied in an explosion of distinct discursivities which took form in demography, biology, medicine, psychiatry, psychology, ethics, pedagogy, and political criticism’ (34). As argued in Chapter Two, this transition is symbolic of the shift from autocratic rule, which enacted power over death, to the more diffuse forms of administrative government which still prevail in contemporary liberal democracies and which exert power over life. As we have seen, this form of biopower became inextricably linked with knowledge, whereby the development of science and statistics provide the means for disciplining individual bodies by way of the surveillance of
the entire population. And, of all the sites of subjectivity in which power became immersed, Foucault believes that sexuality has become the most effective as a mechanism of subjectification and governance.

Sex was a means of access both to the life of the body and the life of the species. It was employed as a standard for the disciplines and as a basis for regulations. This is why in the nineteenth century sexuality was sought out in the smallest details of individual existences; it was tracked down in behavior, pursued in dreams; it was suspected of underlying the least follies, it was traced back into the earliest years of childhood; it became the stamp of individuality - at the same time what enabled one to analyze the latter and what made it possible to master it (Foucault 1978: 154).

It was, thus, through the medicalisation and psychologisation of sexuality that the inner life of the individual, the “natural” state of the body, was brought together in an ‘artificial unity’ with systems of knowledge and power (op cit. 146).

This is the point at which “disability”, “sexuality” and “identity” most clearly converge. Medical discourse has long been recognised as a principal arbiter of the norm (Foucault 1977c; Stiker 1999) and, in providing a ‘bio-physiological definition of “normality”’ (Barnes et al. 1999: 25), it functions to delineate the social strata that particular people are allowed to occupy in relation to their capacities and desires, and, thus, influences how they feel about themselves and how others view them. Those who are able-bodied, heterosexual and attractive are accorded access to positive identities located within what is normal and desirable. Those who lack these qualities are marginalised by way of the ‘bio-mechanical measurements’ in which ‘normality is enshrined’ (Hughes 2000: 559) and, consequently, are forced to inhabit inferior social locations and disabled identities.

When disability and sexuality intersect, the specific marginalisation that results takes one of two distinct, yet connected, forms: the disabled person is categorised as either “asexual” or “perverted”. The connection between these categories relies on their relationship to the norm. As disability is often seen to remove people’s ability to engage in “normal” sexual practices and/or their capacity to incite “normal” sexual desire in others, then, they either cease to be considered sexual beings or, if they persist in behaving in a sexual manner, their desires and behaviour can only be construed in terms of deviance. Other ways of maintaining a sexual identity are rendered inconceivable, unacceptable. As Wilkerson (2002) argues:

The repercussion for those with physical disabilities, like many others, may be silence and unintelligibility, their sexualities rendered incoherent, unrecognizable to others or perhaps even to themselves, a clear instance of cultural attitudes profoundly diminishing sexual agency and the sense of self and personal efficacy which are part of it (46).
As argued in Chapter Three, these silences are just as important to the production of discourse as the things it authorises. Silences, Foucault (1978) argues are ‘less the absolute limit of discourse ... [than] an integral part of the strategies that underlie and permeate discourses’ (27). In this case, what is prohibited for some people acts as a clarification for what is right and good for others. In keeping with its function as the privileged side of a hierarchical dualism, the norm is always defined and reinforced by what it is not.

Foucault (1978) contends that “asexualisation” and “perversion” have been integral, if contrasting, features of the modernist project to connect power, through medicine, to the self. The former he discusses in terms of the sexuality of children. Here he argues that asexualisation has been ‘an important area of contention around which innumerable institutional devices and discursive strategies have been deployed’ and, like all silences, has operated as ‘the counterpart of other discourses, and perhaps the condition necessary in order for them to function’ (30). The same can be said for the asexualisation of disabled people, who have notably been infantilised, not only in relation to their sexuality, but in their reliance on others for their care. Thus, the silences surrounding disability and sexuality are as vital to the production and reproduction of normative discourses as are the cultural images which flood us daily with what constitutes acceptable forms of sexuality, preferred ways of looking and being. The concept of perversion serves a similar purpose. It sets the boundaries around what can be considered to be desirable identities, acceptable ways of being. For the disabled person, the notion of perversion constitutes a double bind. If disabled people dare to think or act as sexual beings, they are at risk of being considered perverted. Yet, even more damningly in some ways, if someone finds them attractive, this person is often construed as a “fetishist”.

In sum, then, Foucault’s work reveals that the construction of boundaries between the sexy and the unsexed, the beautiful and the repulsive, the desirable and the perverted are integral to the dividing practices which fuel the overall process of normalisation. What results is a stratified society where certain characteristics, such as physical capacity, beauty, race, gender and age, are inscribed and continually reinscribed to define the level of respect and self-esteem, even love, that a person can appropriately be accorded. In relation to sexuality, Foucault (1978) talks about ‘specific class effects’ and how sexuality operates differently in different social strata (127). In the case of disabled sexuality, an underclass has developed which, while it has been denied ‘a sexual body’, it has simultaneously been heavily sexualised in relation to perversion, infantalisation, medicalisation and rehabilitation, through - as Foucault argues in relation to children and adolescents - ‘the interplay of presence and a sense, the visible and the hidden’ (153).
The Technology of Sexual Rehabilitation

In researching the sexual subjectification of disabled people in the rehabilitation literature, I selected thirteen texts intended to serve as a reasonably representative sample of the literature in question. As a whole, this literature has been produced by a wide range of health professionals and social scientists since the early 1970s and aims to educate other professionals and/or disabled people themselves with regard to the adverse effects of disability on sexuality and how they might be overcome. It was my aim to choose books reflecting this diversity of timeframe and disciplinary heritage by ensuring that each decade of publication was well covered and each field from which this literature is being produced was represented. Accordingly, the authors range from doctors and psychologists through rehabilitation professionals including physiotherapists and occupational therapists to social workers, community nurses and counsellors.

In selecting the texts, I also wished to include self-help books alongside those written specifically for professionals. Over the past decade it has become increasingly common for professionals to attempt to directly engage lay people in processes of self-actualisation. Appendix Five provides an annotated bibliography of the texts and discusses them in terms of their objectives, disciplinary backgrounds and target audiences. The tone of these texts ranges from expressions of pity to those which suggest empathy and traces of subversion and, as such, some of the texts, as discussed in Chapter Eleven, border on the emancipatory. In analysing the texts, I have merged the categories of appearance and sexuality under the rubric of the latter because what are now being defined as “body esteem” and “sexual esteem” are inextricably linked within the field of sexual rehabilitation (see Taleporos and McCabe 2002).

I argue that a new interplay of presence and absence has evolved over the past thirty years which, although it is ostensibly aimed at liberating disabled people's sexuality by challenging their asexualisation, has the potential to tighten the knot of normalisation. As with welfare reform this is based on the neoliberal thrust towards self-actualisation which encourages the disabled person to take an active role in the building of a positive identity, in this case through the process of 'resexualisation' (Comfort 1974b: 9). Unlike welfare reform, however, sexual rehabilitation is not embedded in economic rationalism and its objectives are not tied to cost cutting strategies or to any overt attempt to increase individual productivity or financial independence. Its points of immersion in the lives of subjects are more diffuse yet infinitely more powerful as they inhabit and symbolise what is believed to be the "core" of human subjectivity and, as such, are seen to be fundamental to every thought, feeling and action. Consider the following descriptions of sexuality drawn from the sexual rehabilitation texts.

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12 Recall the participant narratives which referred to the lack of trust disabled people often had for people who desired them.
Sexuality in its broadest sense is expressed in most of the circumstances in which an individual finds herself or himself on a daily basis: socialising, working, discussions of religion or politics, and raising children (Boyle 1993: 47).

One's sexuality is interwoven throughout all areas of one's life, sometimes in very subtle ways (Sandowski 1989: 23).

Sexuality is important because it is integral to self-image ... for some people, sexuality is how they feel about themselves and how they think others perceive them in terms of attractiveness and desirability. Sexuality can be a basic component of self-identity that can define sexual orientation and lifestyle. It can reflect political positions and human rights policies. It can encompass issues of power and control, affiliation, or hate (Lefebre 1997: 19).

According to these texts, sexuality is omnipresent, all encompassing and a primary site of identification. Working from and through this assumption, sexuality becomes a particularly powerful site through which subjects can be governed. It arises as a key area of expert deliberation and intervention; a key mechanism for recognising, regulating and rehabilitating the behaviours and expectations of disabled people so that they coincide with what is considered "appropriate" to their sexual status.

In annexing the sexuality of disabled people, the field of sexual rehabilitation has based its objectives on two interlocking premises, both of which are stated as guiding principles in all of the texts. The first involves an acceptance and reconfiguration of the notion that disabled people, alongside that of the general population, have been subjected to sexual repression, thus buying into the "repressive hypothesis" criticised by Foucault. The second declares the need for new definitions of and interventions into disabled sexuality based on scientific investigation and knowledge production. The reconfiguration of the repressive hypothesis is a particularly effective governmental tool because, as with welfare reform's claim to offer increased access to social and economic resources, it is built around the idea that the barriers which have created oppression can and will now be removed. Hence the following arguments which, interestingly, remain substantially unchanged despite the passage of time.

Denial and societal attitudes create the major barriers. The waning of Victorianism is levelling these. Sexuality is now recognized as a legitimate area for inquiry and rehabilitation (Erlich 1974: 62).

Interest in sex and the myriad ways to express sexuality are as old as the history of humanity. However, acknowledgment of the existence and importance of sexuality in the lives of physically disabled people, such as those with spinal cord injuries, has been slow in coming (Bruyere 1981: 1)
Though sexuality and sexual behaviour are important to life satisfaction, health professionals still give relatively little, if any, information to clients about sexual functioning and adaptation. Rehabilitation clients clearly need and want this information (Neistadt & Freda 1987: ix).

Sexual messages bombard us daily, yet in professional settings the topic of sexuality is often ignored or is a cause for discomfort (Sandowski 1993: 29).

In Chapter Nine, I argued that welfare reform is a neoliberal technology of the self configured in terms of risk and individual responsibility. I will argue here that the same applies to the technology of sexual rehabilitation. It is increasingly being argued that disabled people who do not receive sexual counselling are at risk of suffering from needless sexual dysfunction (Comfort 1974b) and loneliness (Mooney et al. 1975). Accordingly, the literature specifies that the experts who are being trained to facilitate sexual rehabilitation should encourage their clients to embrace risk rather than, as in the past, allowing themselves to be constrained by it. Flynn (1981), for example, writes about 'the dignity of risk' that disabled people are accorded when 'not being overprotected in either a social or a physical sense' (57), while Mooney et al. (1975) argue that single disabled people will only be able to find partners if they risk rejection and take responsibility for making potential sexual partners feel comfortable. In relation to embracing risk, Greengross (1976) contends that:

> Of course there are dangers. No one would pretend that the dangers do not exist. But allowing individuals sometimes to make decisions for themselves, taking risks and understanding the implications of their actions, can help them to grow as people. Being over-protective is never kind, and is often cruel (8).

Here, just as with welfare reform, risk and responsibility are tightly enmeshed and the ideal neoliberal citizen is encouraged to develop risk management strategies which are based on individual rather than social change (Lupton 1999: O'Malley 1996). This view is clearly evident in the texts. Thus Cole & Cole (1974) suggest that the goal of 'medical rehabilitation', in general and specifically in relation to sexuality, is to facilitate the 'regaining of those abilities which allow resumption of maximum responsibility for one's own life' (41). In the same vein Greengross (1976) argues that: 'The aim of sex education for the handicapped, as for every member of the community, must primarily be to help each individual take responsibility for his own sexual life, and to provide an atmosphere in which the individual can live the kind of sex life he chooses' (93). Thus, although disabled people are being offered access to a sense of sexuality that (may have) formerly been denied them, it is believed to be up to them to achieve it through attitudinal and behavioural change. Consider, for example, the following excerpt from an article which aims to encourage women with disabilities to take responsibility for the problems they experience in forming new relationships.
It is up to a woman to present herself as a full package, to make herself interesting enough so that potential romantic partners will see beyond the stereotypes. Sometimes a woman with a disability has to function in society as an educator and "consciousness-raiser," especially if the people around her are unfamiliar or uncomfortable with disability. This responsibility can seem burdensome, but the results may be well worth the effort (Hwang 1997: 124).

While the notion of individual responsibility may seem to indicate a somewhat solitary pursuit, this is never the case within a neoliberal framework. On the contrary, the process of self-actualisation is forever assisted and promoted by expert guidance. The following section will explore these networks of knowledge and expertise and the discourses which inform them in an attempt to better understand the contemporary connections between knowledge and power.

**Sexual Rehabilitation and Expert Knowledges**

The texts I examined emanated from a wide range of scientific fields and were aimed at a variety of health professionals ranging from doctors and psychologists through rehabilitation specialists, including physical therapists and occupational therapists, to social workers and community nurses. Essentially, however, the discourses which most affect the current reconstruction of disabled sexuality are those which frame what Donzelot (1980) refers to as the “psy” disciplines, and, as such, fundamentally support the notions of individual responsibility and personal change. Hence, each of the texts expresses the belief that, while the impact on sexual ability and sexuality is originally a physical one, the extent of the “problem” and the ability to solve it rests on the psychological state of the individual. Halstead (1974a), for example, claims that '[f]or most persons, whether able-bodied or disabled, attitudes regarding sex present the largest barrier toward achieving a satisfactory sexual adjustment. Helping patients reassess their sexual attitudes can be a very effective therapeutic measure’ (88). And, twenty three years later, Sipski & Alexander (1997) concur that '[t]he majority of sexual dysfunctions originate in reaction to psychologic processes or are compounded by psychologic reaction to organic pathology’ (7).

This “psychologisation of sexuality” can be understood in terms of Rose's (1989) ‘psychologisation of the mundane’ in which no facet of the minutiae of daily living is thought too insignificant for scrutiny and self-reflection, and is integral to the neoliberal notions of freedom, choice and individual responsibility (244). If it is posited that elements of disability have their origins in a person's attitudes and behaviour, then these can only be resolved by changing these ways of thinking and acting. Hence, it is believed that disabled clients ‘need their general attitude to sexuality to be restructured by permission’ (Comfort 1974a: 4), a statement and a goal which reveal the tightly woven governmental phenomena of intervention and choice. It is also suggested that sexual counselling in a rehabilitation setting can facilitate the development
of the full complement of personal capacities, those to which all citizens should aspire. Thus, for example, Cole & Cole (1974) argue that "helping clients to understand their own responsibility in finding sexual satisfaction may foster self-responsibility, maturity and positive actions toward other rehabilitation goals" (42).

In this way, sexual rehabilitation becomes an expertise-driven mechanism for helping individuals to realise their "full potential" with sexuality positioned as a phenomenon intrinsic and integral to the personal aspirations of both the affiliated and the marginalised. This process of rehabilitation involves an intensification of both subjectivity and subjectification, a process which Rose (1989) refers to as the 'government of the soul'. He argues that:

> The government of the soul depends upon our recognition of ourselves as ideally and potentially certain sorts of person, the unease generated by a normative judgement of what we are and could become, and the incitement offered to overcome this discrepancy by following the advice of experts in the management of the self (11).

These experts, described by Rose (ibid.) as 'engineers of the soul', are expected to perform a kind of 'moral orthopaedics' whereby, in the case of sexual rehabilitation, disabled people are to be rendered capable of regaining their sexual identities and achieving fulfilment and a positive self-image (3, 217). Rose argues that these aspirations are created by way of simulacra, where images of desire and desirability are infinitely reproduced via various media and cultural forms to 'provide the template against which the mundane dissatisfactions of our lives, the hesitancies and uncertainties of our speech, the embarrassed awkwardness of our intercourse with others, the clumsy fumblings of our loves and passions are to be judged and found wanting' (239). The technology of sexual rehabilitation, therefore, promises to provide the solutions for sexual inadequacy while, at the same time, constructing a framework for self-reflection and self-creation in which one's self and one's sexuality can never truly be considered a finished product.

Interestingly, in generating the framework of expertise believed necessary to guide sexual rehabilitation, the texts I examined invoke the experts themselves in the process of sexual subjectification. Each of the texts aimed at educating "experts" links the repression of disabled people's sexuality in clinical settings to the sexual repression of the practitioners themselves and demands that health professionals and community workers learn 'to better understand their own sexuality in order to utilize their resources and awarenesses in the treatment of others' (Cole & Cole 1974: 42). Accordingly, Neistadt & Freda (1987) develop a comprehensive list of requirements which outlines the skills, attitudes and knowledge believed to be essential for all rehabilitation professionals to acquire in addressing these limitations.

In order to counsel effectively, you must first be comfortable with your own sexuality and from there progress to achieving comfort with counselling others about sexuality. To feel
comfortable with your own sexuality, you must develop knowledge competencies about the anatomy, physiology, neurology, and development of the human sexual system. You need to be aware of your attitudes toward sexuality, your understanding of sex roles, and your tolerance for different sexual preferences. You must also be able to communicate well with other people and be emotionally open to establishing intimacy in those relationships where you choose to have it (5).

Whether in relation to the engineers of the soul or the engineered themselves, a prime mechanism for resexualisation through education and attitudinal change is the process of calibration and quantification, a process which is common to all contemporary governmental forms. Just as the technology of welfare reform operates through such devices as the work capacity assessment and its associated medical examinations, so sexual rehabilitation is developing its own tools of examination and enumeration. Foucault (1977c) argues that the examination, 'in the form of tests, interviews, interrogations and consultations', has been developed as a disciplinary technology which, although less harsh than the more directly inquisitional forms which preceded it, is equally effective in a disciplinary sense (226). Rose (1989) expands upon this and proposes that by adopting and intensifying the technique of examination, '[t]he psychological sciences … enable the human powers to be transformed into material that can provide the basis for calculation' (48).

What, then, of the 'tests, interviews, interrogations and consultations' that have been devised to make calculable the sites of subjectification which are the focus of sexual rehabilitation? Schover & Jensen (1988), for example, advise that the consultation should begin with a 'sexual assessment' based on 'the multi axial diagnostic technique', a schedule which utilises a set of questionnaires and scales ranging from the MMPI where psychosis is thought to exist to general questionnaires which 'pinpoint the areas of sexual dysfunction' (22, 24, 26). Similarly, Lefebre (1997) recommends the use of 'self-report questionnaires', such as 'The Open Ended Sexuality Limited Organising Worksheet', for 'assessing sexual behaviour' (35). Each of these measurement devices functions to calculate deviations from the norm. According to the 'Multiaxial Problem-Oriented Descriptive System for Sexual Dysfunction', these deviations range from problems during 'the desire phase', such as 'low sexual desire' and 'aversion to sex' to problems during 'the arousal phase' such as 'decreased subjective arousal', 'decreased intensity of orgasm, and the state of being 'coitally inorgasmic' (Schover & Jensen 1980:57). Once the "problem" has been adequately quantified and clarified, 'precise testing measures may be employed to give patients specific rather than vague counselling' and 'a precise prescription for sexual activity' devised (Mackey 1974: 107, 106).

In the spirit of perpetual re-examination and reassessment, the process of sexual rehabilitation must be continually monitored to measure its efficacy. Flynn (1981) describes, for example, a method for 'evaluating agency success in promoting normative sex behaviour' through the application of the 'Program Analysis of Service Systems' which is referred to as 'an evaluation
instrument [which] can assess the degree to which [medical professionals] are successful in fostering normative behaviour, including normative sex behaviour’ (49). Experts are also expected to subject themselves to examination using similar processes of measurement and assessment. The Sexual Attitude Reassessment (SAR) Program, for example, is aimed at doctors and health professionals to help them ‘re-evaluate their personal and professional feelings regarding sexuality’ (Halstead 1974b: 256), and, more recently, it has been suggested that successful sexual rehabilitation requires ‘an ongoing institutional commitment to train all staff who have contact with patients on basic sexuality issues’ (Sipski & Alexander 1990:7:9).

It is important to note that all of these processes of examination require both clients and practitioners to speak with increasing openness about sex and sexuality, a process which rests on a further transformation of the ‘interplay of presence and absence, the visible and the hidden’ (Foucault 1978:153). In drawing the parallel between this kind of personal examination and the Catholic practice of confession, Foucault (1978) quotes from Segneri’s book on religious instruction (1695).

Examine diligently, therefore, all the faculties of your soul: memory, understanding, and will. Examine with precision all your senses as well... examine, moreover, all your thoughts, every word you speak, and all your actions. Examine even unto your dreams, to know if, once awakened, you did not give them your consent. And finally, do not think that in so sensitive and perilous a matter as this, there is any thing trivial or insignificant (Segneri as quoted in Foucault 1978: 20).

In expanding on this, Rabinow & Dreyfus (1982) argue that ‘confession, and especially the confession about one’s sexuality, [became] a central component in the expanding technologies for the discipline and control of bodies, populations, and society itself’ and that ‘[t]hrough it, the most particular individual pleasures, the very stirrings of the soul could be solicited, known, measured, and regulated’ (176).

The new intermediaries in the contemporary form of Foucault’s (1982) ‘pastoral power’ are the doctors, counsellors, social workers and rehabilitation specialists (212-214). And, as with its priestly origins, ‘this form of power cannot be exercised without knowing the inside of people’s minds, without exploring their souls, without making them reveal their innermost secrets’ (Foucault 1982: 214). True to their mission, all of the texts I analysed began with a discussion of how to initiate this process of disclosure. For example, Schover & Jensen (1988) answer the question: ‘How can we reach the 90% of patients with problems who currently receive no help?’ by suggesting that ‘[t]he key is the primary care team's ability to bring up the topic of sex and to make patients feel comfortable in discussing a problem’ (106). And, similarly, Comfort (1974b) argues:
If physicians recognize that early resexualization is as important as early ambulation, and inquire diligently and tactfully into the sexual adaptation of patients, they can perform important therapy in limiting unnecessary dysfunction, and equally important research in detecting other common and remediable psychosexual problems of illness which their patients have been suffering in silence (8-9).

This initial stage of encouraging clients to talk about their sexuality is implicit in the primary counselling technique advocated within all of the texts which are directed at educating sexual rehabilitation experts and known as the PLISSIT model where the “P” stands for the “permission” to talk about sexuality. Renshaw (1974) argues that this ‘permission from a respected authority to look at, know, touch, understand the sexual self (and at home to enjoy it)’ can ‘obliterate the ignorance of a lifetime’ (128).

Self-help, Self-esteem and the Leaky Borders of Emancipation

Increasingly, sexuality has become a matter for discussion and self-examination outside of clinical settings. Facilitating this extension and diffusion of expertise into the mechanics of daily living is the field of self-help literature. While the texts directed at experts are intended to aid resexualisation from within the framework of the clinical setting, those which can be classified under the rubric of self-help literature attempt to intersect with the governance of the soul at a more self-initiated level. Subjects of self-help are no less exposing themselves to expert knowledges: they are simply engaging with them in a process which operates at a greater distance from the source of expertise and which, as such, appears to privilege a higher degree of freedom, autonomy and choice. It is possible, however, that in some way this distance is closing given that doctors and psychiatrists are beginning to prescribe self-help books as part of the treatment process (Cambell & Smith 2003; Dobson 2003).

Of the fifteen texts analysed here, three follow what I would define as a self-help format, those authored by Kahane (1990), Kaufman et al. (2003), and Kroll & Klein (1992). As a corpus, self-help books, share certain basic elements in their structuring and tone. Although generally written by people who have academic qualifications, their discussions and prescriptions are developed around common sense applications of scientific knowledge and draw on anecdotal evidence which usually stems from informal opinion gathering. Thus, for example, Kaufman et al. (2003) use what they call a ‘highly unscientific survey’ to provide the lengthy quotes around which they structure their text, The Ultimate Guide to Sex and Disability (x). And, in self-help texts, the arguments for personal change are presented in what might be described as a “recipe format” where the possibilities for liberation and/or self-actualisation are structured in terms of a series of steps. Additionally, the reader is often invited to participate in exercises intended to aid in their learning process. This usually takes place at the end of each chapter.
In the academic literature, self-help books have been criticised for perpetuating normative prescriptions (Ebben 1995; O'Connor 1995; Schrager 1993; Zimmerman et al. 2001), for individualising social problems (Singleton 2003), and, in the governmentality literature, they have been analysed in relation to the ethical framework in which subjectification occurs (Cruikshank: 1996; Hazledon: 2003; Rimke: 2000). All of these observations are pertinent to the self-help books focused upon here. Kroll & Klein (1992), for example, continue to maintain an individualistic focus while arguing for emancipation. Hence they propose that ‘you can choose to have a proud, positive self-concept or a weak, distorted opinion of yourself’, affirming a process of self-actualisation which places heavy and ultimate responsibility on the individual concerned. Thus, they argue:

Maintaining this inner dialogue with yourself, a conversation filled with calm reassurance and positive self-affirmation, is only part of the battle. This foundation must be strengthened by constant reminders from within that a disabled person has every right to a complete and fulfilling life, including a sexual life, no matter how he or she outwardly varies from society's ideals of physical attractiveness. A person with a disability has to both act and feel confident, letting others know that he or she will not be treated as a second-class citizen (238-239).

In a similar vein, Kaufman argues that:

It is very difficult not to internalise negative messages, not to consider ourselves lacking in comparison to the dominant norm. We can do several things with these messages. We can give ourselves more positive messages, and take compliments when they are given. We can listen to what people who feel good about themselves have to say and use that as a cue to actively speak about ourselves in a positive way. We can try to think about ourselves as attractive, desirable, worthy and good (16).

Once again, there is an acknowledgement of the social causes of a negative self-image, but the solutions are still seen to exist purely in the process of individual change in keeping with Gloria Steinem’s (1992) ‘revolution from within’. These arguments for inner change all come from chapters in the texts dealing specifically with self-esteem and, as such, pivot precariously on the boundary between the development of emancipatory strategies and those which only serve to reinforce the norm.

Adelson (1996) has observed that all self-help texts, regardless of their specific point of focus, are essentially about self-esteem. He recalls visiting a local bookshop, expecting to find at most a shelf of self-help books on self-esteem, but, instead, discovers 49 shelves and a total of 1,000 books. He describes them as follows:

Almost all were less than five years old, and almost all offered practical help: how to protect your self-esteem, improve your self-esteem, repair your self-esteem; seven
steps, ten steps, twelve steps to a better view of yourself; self-esteem through physical fitness or a more balanced diet; how women should deal with men who damage their self-esteem; how to guarantee the self-esteem of your children; how to recover self-esteem after losing your job, or your fiancée, or your spouse (34).

The self-help books I reviewed here were no exception. While they each have a distinctly political edge which is largely consistent with disability rights principles and the social model, all, ultimately, came to rest on the premise that change must come from within and that, indeed, it is each person's responsibility to improve their self-esteem. In this way, and as Cruikshank argues (1996), '[p]ersonal fulfilment becomes a social obligation in the discourse of self-esteem according to an innovation that transforms the relationship of self-to-self into a relationship that is governable' (239).

How then, if individual change can only be construed as a mechanism of government, is emancipatory action aimed at enabling disabled identities to be understood and initiated? If self-esteem is a particularly powerful normalising concept and empowerment is, in reality, a top-down process which uses expert knowledges to distance the subject from power while intensifying and multiplying its points of access, how can we ever become agents in our own self-creation? Within a social structure which enmeshes citizens ever more deeply in networks of power through their apparent freedoms and choices, any claim to liberation can appear to be a chimera, an illusion. With these questions in mind, I will conclude this discussion and, to a great extent, my thesis by further exploring the concepts of "self-esteem" and "empowerment" in relation to the technologies of sexual rehabilitation and welfare reform. In this respect, I aim to tease out the differences between what may be construed as emancipatory and what can be argued to constitute an ever more pervasive, yet more subtle compact with the norm.
In Chapter Three I argued that identity is the key mechanism for inserting social meaning into personal experience and, as such, can be defined as the main conduit linking power to subjectivity. I have now arrived at a point in my analysis where I believe it will be possible to fully grasp the intricacies of how this process of subjectification is engineered. My suggestions are twofold. First, “self-esteem” is the concept, the point of insertion as it were, through which governmental access to subjectivity is gained and, second, “empowerment” is the process by which this linking of governance to the inner worlds of individuals is achieved. Thus, I am arguing that under a neoliberal framework the identity of citizens is created through technologies of the self like welfare reform and sexual rehabilitation which seek to act upon the self-esteem of individuals by way of their empowerment. I also propose that, by fully appreciating how these processes of subjectification operate, we can choose otherwise. In other words, as Foucault (1988g) argues in relation to identities, ‘they can be unmade, as long as we know how it was that they were made’ (37).

Self-esteem holds a place in our lives which is at the heart of our identities. It can appear to be, paradoxically, both an essential human quality and a form of self-belief over which we can ultimately exercise a great deal of control. Kroll and Klein (1992) define self-esteem as ‘the feelings we all have about our physical and emotional selves’ (35) and Nosek & Hughes (2001), in their study of how disability affects the self-esteem of women with disabilities, record that self-esteem has be described variously as ‘personal self-regard (Bednar & Peterson, 1995), attitude toward one's self (Rosenberg, 1965), and the evaluation of one's self-concept as positive or negative, neutral, or ambiguous (Frey & Carlock, 1989)’ (20). They end by following Leary & Downs’ (1995) notion in proposing that self-esteem is ‘how we assess our worth and competence, in terms of how we think, feel, and act’ (20). From a different perspective, Cruikshank (1996) points out that ‘[s]elf-esteem is a technology of citizenship and self-government for evaluating and acting upon our selves so that the police, the guards and the doctors do not have to’ (234). It is a particularly powerful concept or technology because, as Rose (1989) points out in relation to the government of the soul in general, it ‘binds subjects to a subjection that is the more profound because it appears to emanate from our autonomous quest for ourselves, it appears as a matter of our freedom’ (256).

The ubiquity of self-esteem as a guiding concept is not confined to the self-help texts alone. It is fundamental to the broader field of literature which informs the technologies of welfare reform and sexual rehabilitation. Accordingly, a basic plank in the platform which supports the technology of welfare reform is the belief that one must work or at the very least actively
Participate in one’s community in a voluntary capacity to build one’s self-esteem. Both the interim and final drafts of the McClure Report begin with the following argument:

Participation in paid employment is a major source of self-esteem. Without it, people can fail to develop, or become disengaged from, employment, family and community networks. This can lead to physical and psychological ill health and reduced life opportunities for parents and their children (FaCS 2000a: 4; FaCS 2000b: 3).

Reminiscent of Rose’s (1996b) observation that welfare recipients have been reconstructed through the rationality of neoliberalism as ‘people whose self-responsibility and self-fulfilling aspirations have been deformed by the dependency culture [and] whose self esteem has been destroyed’ (59), the Australian Government makes the argument that welfare reform aims ‘to rebuild the self-esteem of people whose self-image may have been damaged by their lack of paid employment’ (FaCS 2000a: 55).

The sexual rehabilitation texts also claim that self-esteem is a pivotal quality which is both damaged by lack of access to full neoliberal citizenship, in this case in terms of an adequate sense of sexuality, and in need of restoration if one is to achieve or regain it. Sipski & Alexander’s (1997) claim is characteristic here: ‘perhaps the most important factor in people’s psychological well-being is that of self-esteem. Disability affects the way in which people feel about themselves. If their self-esteem is damaged, their sense of sexuality will certainly be similarly affected’ (7). In the case of both welfare reform and the rehabilitation literature, we also have the argument that the gaining or regaining of self-esteem is seen to be a matter of individual responsibility and, ultimately, a necessity, which, as Kahane (1990) argues, ‘depends largely on your individual strengths and weaknesses’ (182).

Hence, poor self-esteem is believed to be both an off-shoot of, and a reason for being, unemployed, dependent or sexually inadequate. Accordingly, it is not only claimed that a good self-esteem can be regained by getting a job, becoming self-reliant and recovering one’s sexuality, but even more significantly, in keeping with the notion of individual responsibility, that developing a good self-esteem is a necessary, and even at times a sufficient, ingredient for securing employment, independence, sexual attractiveness and sexual satisfaction. A healthy self-esteem is increasingly being seen as a panacea for all ills and the “prescription” for obtaining one constructed in terms of empowerment. Consider the following claim made in one of the sexual rehabilitation texts:

Sexual independence is an extremely potent form of empowerment. It is our belief (and our personal experience) that, by exploring our sexuality, by deciding that we are worthy of feeling pleasure and of realising our possibilities as sexual beings, we can change other parts of our lives as well (Kahane 2003: xii)
The entry of “empowerment” in this context is particularly noteworthy as, in practice, empowerment is rarely perceived as a solitary pursuit. It is invariably attached to expert guidance and, therefore, any kind of independence that can be said to have resulted from it can only be understood as a facilitated form of freedom. As Rose (1996c) argues, it ‘has come to encompass a range of interventions to transmit, under tutelage, certain professionally ratified mental, ethical and practical techniques for active self-management’ (349). Cruikshank (1996) makes the same point: to become “empowered”, individuals must ‘accept the responsibility to subject their selves, to voluntarily consent to establishing a relationship between one’s self and a tutelary power such as a therapist, a social worker, a social programme, a parenting class or what have you’ (Cruikshank 1996: 234). This attachment of empowerment to those who are qualified and sanctioned to empower, that is, the engineers of the soul, is nicely illustrated in this extract from another of the sexual rehabilitation texts.

The emphasis social work places on holistic intervention on behalf of clients along with an empowerment oriented intervention strategy, uniquely prepares social workers to help clients with disabilities and their partners cope with the many psychosocial changes that accompany disabilities. Social workers who are prepared with counseling skills and disability specific sexual knowledge can have a major influence on positive psychosexual development and adjustment of clients with disabilities and their partners. It is up to the profession and up to individual social workers to meet this important need (Mackelprang 1993: 86-87).

This connection between the government of the soul and its engineers is also evident in the literature which guides current welfare reform policy. The Final McClure Report (FaCS 2000b), for example, states that its main objective is empowerment and makes clear that this process will require the expertise and intervention of a great many professionals.

Our vision is for a service delivery model that is enabling, rather than a system that encourages reliance. An important part of building individual capacity and working towards self-reliance is empowering and enabling people to identify their hopes and aspirations, and negotiate the steps they need to make in order to participate. This involves the individual working with the assessment agency and, as appropriate, brokers and other service providers, to develop participation plans and making informed decisions about the most suitable type of service intervention (14).

Shaver (2001), who is critical of these claims to empowerment, argues that the McClure Report ‘saw the role of welfare as to enable, empower, and finally enforce, social or preferably economic participation on the part of those at risk of social exclusion’ and that ‘the darker side of this communitarian vision’ is its ‘paternalistic supervision and compulsory community at the expense of individual rights and freedoms’ (277). He thus directly challenges the assumption that welfare reform will enhance personal freedom and individual rights. It is to the relationship
between individual freedoms and paternalistic interventions that the remainder of this chapter is devoted.

“Empowerment” as Fostering Powerlessness

“Empowerment” is a term used both by those who seek to increase the points of intervention in disabled people’s lives and by those who aim to disengage themselves from such intervention. As a mechanism of government it can be said to lack the qualities of a truly emancipatory strategy because it operates to reinforce the dominant discourse rather than challenging it, channels power from above rather than allowing it to emerge from below, individualises social problems and, thereby, neglects to address the structural causes of marginalisation in its development of strategies for change. It is a potent mechanism because it appears to offer a great deal to those who have been denied access to social resources and positive identities. However, when the veneer of freedom and choice is stripped away to reveal its core values, it can be shown to reinforce many of the qualities and states of existence that it ostensibly seeks to combat.

Powers (2003) argues that while supporters of empowerment argue that it counteracts paternalism, ‘in practice ... empowerment equals paternalism’ (230). In most cases, the empowerment strategies inherent in the technologies of welfare reform and sexual rehabilitation construct experts as educators, guides or, at the extreme end of the scale, agents of enforcement who need to overcome various forms of resistance and ignorance from their clients in the effort to offer their superior knowledge. Recall, for example, the argument, by no means uncommon throughout the sexual rehabilitation texts, that ‘some [disabled clients] will need their sexual attitudes to be restructured’ and that this can only be understood in terms of their ‘compliance’ or ‘non-compliance’ with normative goals (Comfort 1974a: 4, 5). Recall also the welfare reform argument cited earlier that some people will require ‘persuasion’ and ‘encouragement’ and ‘the most resistant group may need to be compelled to consider and ultimately to undertake a course of activity that might lead towards greater self-reliance’ (FaCS 2000a: 57). Hence, Powers (2003) is able to claim that empowerment strategies provide ‘the illusion of choice’ while, in reality, functioning to justify coercion (235). Similarly, Beresford & Holden (2000) refer to empowerment by experts as ‘the new form of paternalism’ and accuse it of being ‘prescriptive, directive and top-down’ and, at times even ‘authoritarian’ (981-982).

To fully appreciate how such an apparently liberatory strategy can conceal such oppressive underpinnings it is necessary to return to the earlier arguments about ‘risk management’ in neoliberal terms. In this context, Powers (2003) talks about the capacity of empowerment to create ‘pathologized identities’ based on the construction of a ‘pathologized at-risk situation’ (235). In other words, by being construed as at-risk of long-term unemployment, long-term dependency, asexuality and/or perversion, disabled people are seen to be both in danger and a danger to others, claims which justify intervention in their lives and legitimise the formation of a
conduit between their hopes and aspirations and the goals of normalisation. Over and above this, though, disabled people are reconstructed as (potential) neoliberal subjects who must embrace risk rather than seeking to shield themselves from it. This means that they are expected to actively engage with whatever forms of expertise are believed capable of helping them restore their self-esteem so that they will be equipped to pursue their self-actualisation.

To make matters worse, the imperative of “self-actualisation” is itself fraught. In Chapter Five I discussed the double bind involved with encouraging people to talk about their losses. My participants were so programmed to avoid pity that they were loathe to talk about their feelings of disenfranchisement and many of the participants initially tended to refer to themselves only in terms of triumph or intended triumph. It was only in the deeper discussions which ensued that the costs of stoicism, negation and super-cripdom were volunteered as topics of conversation. The pressure to triumph over one’s disability in the name of self-actualisation is immense. Experts contribute to this when they incite the sick and the disabled to overcome their obstacles, a practice exemplified in the following quote from Kleinman, a doctor who writes extensively, both to other professionals and disabled people themselves about the need for empowerment in the face of chronic illness and disability.

To maintain one's aspirations in the face of grave adversity, to work hard to contend successfully with the daily assault of an impaired body on a robust spirit, to be victorious over the long course of losses and threats that constitutes disability - these are lessons for us all, examples of what is best in our shared humanity (Kleinman as quoted by Rose 1996c: 349).

By its very nature, this kind of reasoning tends to silence other narratives. For, as it was pointed out in Chapters Six through Eight, how can one argue against the prevailing values in relation to work, independence and appearance/sexuality without appearing to be lazy, passive or, in the case of sexuality, suffering from a case of sour grapes or perversion? Or, as Foucault (1988g) argues, ‘How can the truth of the sick subject ever be told?’ (29). This process of silencing is acknowledged by Couser (1997) who writes that the autobiographies of disabled people ‘may not in fact be very representative - in other words, typical - of those with disabilities’ because ‘[t]here is a strong temptation - fed both by the needs of the ego and the literary marketplace, which prefers such narratives - to adopt the hegemonic narrative paradigm of transcendence over bodily injury rather than to challenge its cultural construction’ (183, 198). In relation to the dozens of autobiographies he analysed, he notes that:

All display a male pattern of concern with individual autonomy and freedom; all in various ways base their comic plots on some sort of intellectual, emotional or spiritual compensation for the loss of physical mobility. None of the narratives examined thus far, then, goes out of its way to affirm solidarity with a marginalised group or to question the
cultural ideals of individualism and independence; each autobiographer comes to terms with disability - denying, transcending or side-stepping stigmatisation - on his own (198).

This pressure to conform, to normalise and to triumph results in, or, perhaps, more accurately, results from, what has been referred by Jacobs (2002) as ‘the manufacturing of “disabled heroes”’ (71). Wendell (1997) defines ‘disabled heroes’ as ‘people with visible disabilities who receive public attention because they accomplish things which are unusual even for the able-bodied’ (271). She goes on to argue that those people who can be seen to “triumph” in this way are usually in possession of large material wealth and exceptional circumstances and that the presentation of these people as symbols of what all disabled people can attain is ultimately extremely disempowering for disabled people in general. This brings to mind one of the participant’s observations, quoted in Chapter Seven.

We have here in New Zealand a Blind gentleman, that has been seen on TV using a chain saw to top a tree. The question immediately is asked, “Can you do that?” The next question is “why can’t you do that?” The next statement is “You ought to be able to do that.” Next “You must do that”, and when you say “I can’t do that,” they hit back with “Can’t means won’t, you are a welfare bludger, who just doesn’t want to work.” Now, from a Blind perspective, that chain sawing gentleman may be able to use his saw to top a tree, and if he feels comfortable doing such things, that’s fine, but don’t let anyone think that he represents the rest of the Blind community. The vast majority couldn’t do what he does. Most wouldn’t be silly enough to attempt it (Craig written story: 17).

As well as increasing ‘the "otherness" of the majority’ (Abberley 1999: 271), the imperative to triumph is often very damaging to the “heroes” themselves. Hillyer (1993) argues that becoming a Super Crip usually relies on the person “passing” as normal as is possible. This involves a certain degree of deception, both in relation to others and oneself - a practice which can only be maintained at great personal cost.

Deception is demoralising, anxiety provoking, and harmful to the passer’s health and relationships. It also deprives society as a whole of knowledge about diversity. Passing involves adopting the values of the privileged group; it causes "emotive dissonance"; it is harmful to mental and physical health; it makes the secret the central focus of the passer’s life; it harms relationships with those who know the secret and with those who do not; it makes it difficult to know who your friends or enemies are; and it maintains the very repressive system that causes it (150).

The costs of such practices are reflected in the stories told by Hugh Gallagher (1998), Robert Murphy (1990) and Karen, recounted in Chapter Five, all of whom eventually suffered from both emotional and physical breakdowns as a direct result of pursuing the heroic path for a great many years. In their case, all learned to recognise the trap inherent in the triumph narrative and found other identities to develop, other stories to tell. Hugh Gallagher (1998)
expressed this very vividly when he wrote of his decision to let go of FDR as his hero: ‘FDR was a great man, a magnificent leader of world scale, but he was no longer my role model. He was Super Crip; I opted for human’ (209).

Powers (2003) argues that it is its entrenchment in individualism which separates empowerment from strategies that possess genuine emancipatory potential. She traces the misuse of the word “empowerment” in relation to its origins in the work of Paulo Freire. She argues that, although most people who defend empowerment as a liberatory strategy do so because they attach it to Freire’s concept of liberatory education in Pedagogy of the Oppressed, Freire himself argued against ever considering empowerment to be anything other than a process of social change. When asked by Ira Shor: ‘There is no personal self-empowerment?’ He replied with vehemence:

No, no, no. Even when you individually feel yourself most free, if this feeling is not a social feeling, if you are not able to use your recent freedom to help others to be free by transforming the totality of society, then you are exercising only an individualist attitude toward empowerment or freedom (Shor & Freire 1987: 109).

Neath & Schriner (1998) take a similar view when they argue that ‘an exclusive or primary focus on individual empowerment by disability professionals violates the spirit of the disability rights movement which is a political movement organizing for social change’ (217). They then go on to make the case that:

The vast majority of individuals in our society are quite limited in the amount of power (empowerment) available to them, regardless of how ‘empowering’ their attitudes, personality and behaviors may be, because of the hierarchical structure of the society (where political and economic power is concentrated in the hands of a relatively small and elite group of people). The disability rights movement, as a social movement, recognizes the need for individuals to work together in order to change the power dynamics at work in the society. Looking at empowerment as a characteristic of individuals incorrectly suggests that the most important kinds of power will be gained by individuals, rather than through widescale social change (218).

This means that if we are to develop strategies which can potentially lead to the development of an identity which is no longer disabled by internalised oppression, we have to shun all promises of empowerment which are paternalistic, individualising and normative. This can hardly be claimed to be a straightforward process because emancipatory processes are very tightly woven within neoliberal structures and, as such, it is not easy to separate false from real potential. Yet, I do believe that if counter-narratives are shaped and continually reshaped within a critical genealogical framework, then it is possible to develop subject formations which do not
perpetuate marginalisation. I even believe that, ultimately, it is possible to devise individual responses to oppression which are socially contextualised and, therefore, emancipatory.

**Enabling the Disabled Identity**

Our relationship with ourselves will change when powers that have worked secretly are revealed. They can never have the same kind of force, even if they continue to influence us (Ransom 1997: 58).

The question I set out to answer when I began my project was, how can we better understand the identity losses which are experienced by people who become disabled and how can this understanding lead to better lives for disabled people? What has emerged from the attempt to answer these questions is the recognition that disability forms a pivotal part of the construction of both preferred and marginalised identities and that to challenge the imposition of the disabled identity requires the disruption and displacement of the central values which govern the objectives of contemporary neoliberal citizenship. It is this recognition which is at the heart of how one separates what is emancipatory from what remains oppressive. Accordingly, and as I have argued throughout, I believe that the fundamental tool for enabling the disabled identity can be said to be the genealogical practice of ‘deconstructing necessity’ (Couzens Hoy 1998: 31) because it makes it possible for us to understand the nature of our subjectification so that we can ‘promote new forms of subjectivity through the refusal of [the] kind of individuality which has been imposed on us’ (Foucault 1982: 216).

I am in no way suggesting that this should entail a denial of the importance of self-esteem or the stultification of any attempt to improve upon it. But we need to undergird this process of re-identification with the recognition that our identity is a social creation which is in continual process with governmental forms and that to exercise any kind of agency we will need to be ever vigilant in our awareness of how the dominant discourse affects our inner worlds. By being cognisant of the nature of the “empowerment” being offered by the experts who guide welfare reform, sexual rehabilitation, medical treatment and self-governance in general, disabled people can choose to exercise power in the operation of these relationships and to discern what is and what is not in their best interests. Key to this ability to engage with power in liberatory ways is the knowledge that resistance can be applied at any point at which power operates (Foucault 1978). I believe that there is nothing, no matter how oppressive, that we cannot at some level subvert or reconstitute in ways which loosen the ties that bind subjectivity to subjection as long as the process remains a collective endeavour constantly informed and reinforced by genealogical insights.

What makes this project always challenging and often confusing are the difficulties which arise from attempting to develop liberatory strategies within the main framework of meaning available, that which structures the dominant discourse. In Chapter Three I argued that it is possible and,
indeed necessary, to develop new discourses and languages from the subjugated knowledges, both discursive and narrative, which evolve from the genealogical project. However, it is also the case, as Foucault (1980d) points out, that ‘the particular elements of the knowledge that one seeks to disinter are no sooner accredited and put into circulation, than they run the risk of re-codification, re-colonisation’ (86). He goes on to argue:

In fact, those unitary discourses, which first disqualified and then ignored them when they made their appearance, are, it seems, quite ready now to annex them, take them back within the fold of their own discourse and to invest them with everything this implies in terms of the effects of knowledge and power (ibid).

This recodification and recolonisation is particularly evident in the incorporation of the language of disability rights in the framing of welfare reform policy, and, in reverse, in the clearly neoliberal underpinnings of certain planks in the disability rights platform in relation to employment and independence. Rose (1996b) refers to the latter in terms of a “reversibility” of relations of authority by which he declares, ‘what starts off as a norm to be implanted into citizens can be repossessed as a demand which citizens can make of authorities’ (58). This is clearly evident in the claims of some disability theorists and rights activists that disabled people will only be liberated through employment, that welfare support encourages unhealthy dependence and that sexual esteem and body esteem can only be developed through strategies which rely on individual change.

This is why it is essential to retain a reflexive and entirely critical attitude towards the values which underpin any promise of liberation. Once there is an awareness that identity is socially constructed within a particular cultural and historical framework that is dynamic and extremely adaptive to attempts to resist it, it is possible to build new identities within the fractures and fault lines out of which power erupts and along the borders of the norm where metaphors can be devised to create new meaning, new identities. It is through having become marginalised that the disenfranchised ultimately wield more power to disturb the status quo than the “normate”, because, by having been forced to live at the edges of society, the oppressed occupy a location which lends itself to the disturbing of these boundaries and the building of tensions which can cause new fault lines to erupt. I believe that this is what Foucault (1988g) touches on when he writes about the ‘virtual fractures’ which ‘open up the space of freedom’ (37), and, later, when he discusses what is involved in the development of ‘a critical ontology of ourselves’ (Foucault 1991f: 47). He writes:

I mean that this work done at the limits of ourselves must, on the one hand, open up a realm of historical inquiry and, on the other, put itself to the test of reality, of contemporary reality, both to grasp the points where change is possible and desirable, and to determine the precise form this change should take (italics mine) (ibid).
I believe that what Foucault refers to as ‘the limits of ourselves’ are the margins, the borders and the fractures that define and potentially disrupt normative subjectivity. And, by continually shifting our attention between the historical elements of subjectification and the localised points at which its disruption can be struggled for in the present, Foucault believes that we can begin to answer the question: ‘How can the growth of capabilities be disconnected from the intensification of power relations?’ (op. cit. 48).

One of the primary means for combining social, historical and individual levels of awareness, one which provides a very powerful position from which to redefine disabled identities, is the formation of coalitions of resistance. The disability rights movement and the field of disability theory which draws from and informs it, for example, although representative of a great many, often conflicting viewpoints, share the belief that disability is a social construction that can be challenged through social change and it is in this awareness of the social nature of oppression that the possibility for emancipation resides. Oliver (1996) argues that a truly liberatory form of “empowerment” can be developed if the quest for individual change is combined with the social awareness which results from both the consciousness raising and the potential for political action which are integral to the process of what he refers to as ‘collective empowerment’ (147).

Indeed, the process of genealogy itself is not a lone enterprise performed by isolated individuals. The collective nature of this enterprise may often be disguised by the disciplinary differences which exist between conflicting schools of thought and the all too often competitive, individualistic character of intellectual pursuit. Yet, it is essentially a cooperative process which relies on the research and inspiration of a great many theorists who build on each other’s work. The genealogical project surrounding disability has involved a variety of theoretical strands, not least of which are those informing the inclusion of personal experience in the production of sociological knowledge, the recognition that disability is a social construct deriving from modernity’s imperative of labour and creation of the norm, and the provision of the tools which allow for the deconstruction of modern subjectivity. The theoretical bases and practical objectives of these schools of thought may often be at odds with one another. Yet, they are nevertheless part of a collective process which opens the way for the development of emancipatory thought and action. Only by our reciprocal engagement can we make the connections vital to our eventual leaps in critical insight.

Many components of the disability rights movement and disability theory have emancipatory potential because they grasp the importance of the social context and are directed towards developing new understandings of power. Neath & Shriner (1998), for example, argue that disabled people need to extract themselves as much as possible from paternalistic structures where some people exercise ‘power over’ others and, instead, to devise more egalitarian forms where ‘personal power’ is developed through structures, based on the notion of ‘power with’, where power is shared equally among stakeholders (219). While Neath & Shriner’s work is
directed towards the creation of egalitarian workplace structures, Prilleltensky (1996) takes up the same themes at a personal level when she argues for the application of the principles of ‘feminist therapy’ to the lives of disabled women. Here she proposes that the usually oppressive underpinnings of psychotherapeutic practices can be rendered emancipatory by incorporating a ‘political analysis of psychological distress, [the] equalisation of power, and [the inclusion of] social action’ (88).

While coalition building and collective action are vital, it is also important not to develop overarching claims which negate individual differences and not to return to the view, perhaps all too common within identity politics, that identities are natural and that solutions to any form of oppression should be universal. This means that a particular relationship needs to emerge between what Foucault (1988j: 50) calls individual ‘practice of liberation’ and the wider coalitions of which they form a part, yet, in a sense, always remain distinct from. On this, Foucault argues that individual practices need not, and, in reality, cannot operate in isolation from group strategies and, in relation to the task of critical theorists and their development of intellectual tools, suggests that ‘by forming groups specifically to make these analyses, to wage these struggles, by using these instruments or others: this is how, in the end, possibilities open up’ (Foucault 1988c: 192). Accordingly, as is articulated by McNay (1992) in relation to Foucault, “[c]oalitions are not ruled out, but a relational understanding of identity reminds us that any common struggle is a democratic and provisional one. Subject to recreation and renegotiation’ (111).

This brings me back to the central difficulty which framed Chapter Four, namely that it becomes very problematic to claim unity because it tends to reproduce the exclusionary practices which have served to create our divisive identifications in the first place. In that chapter I argued that, to avoid the pitfalls of identity politics, it is preferable to avoid seeing the solution to oppression in the creation of a new more positive disabled identity, worthy of celebration and based on pride. Rather, in keeping with the recognition that the disabled identity is socially imposed, we must aim to rid ourselves of it altogether. Thus, the enablement of the disabled identity actually entails its dissolution. To achieve this may well require a joint consciousness and group action, but this would be better served by forming partial and temporary communities of resistance rather than groups which are believed to be based on a natural and ongoing connection. And these communities of resistance must be capable of changing their shape in response to the differing circumstances within which subjugated identities are framed.

Foucault (1991a) has argued that effective liberation movements do not discover the core of the human personality, they make possible the ‘destruction of what we are... [and] the creation of something entirely different’ (122). However much the technologies of welfare reform and sexual rehabilitation promise in the way of personal liberation, this cannot be achieved by renaming disabled people “at risk of long-term unemployment” and/or “subjects of
resexualisation”, for these categorisations only serve to deflect our attention from the real sources of their oppression, thereby deepening it. On the contrary, it involves removing disability as the primary source of identification, opening up all the other sites of identity formation which can define people outside of their impairments and building a social structure which is based on interdependence and autonomy.

It is vital, however, to avoid the inevitable collapse into a Utopian vision that a universal hope for a better world entails and, instead, recognise that individual and political struggle for change can only ever operate through fleeting, localised strategies which seek to disrupt power at its diffuse and multiple points of interface with daily life. I argue that this involves the creation of alternative spaces and discursive challenges which can break through the surface of hegemonic structures, disrupt them, dissolve and re-emerge repeatedly in ever shifting forms in varying locations in response to the chameleon nature of power. Caines (2003) describes these momentary and partial sites of contestation as ‘guerrilla’ in nature. Foucault (1997) calls them ‘heterotopias’ and suggests that by creating them or becoming aware of those already in existence, all of the overlapping meanings of a concept or a particular space can be ‘at one and the same time represented, challenged and overturned’ (351).

Yet, the question remains: in practical terms, how we can equip ourselves to respond to technologies of the self in ways which do not deepen our oppression? Based on my reading, I suggest that we need to engage with them with a critical eye for what can be useful and what must be challenged or discarded. I was struck, for example, by how closely woven together are liberatory possibilities and the normative prescriptions in many of the sexual rehabilitation texts. This made me realise that, while these texts should never be simply accepted, it would be equally wrong to discard them in their entirety. Kaufman et al. (2003), for example, although they largely follow a highly prescriptive “recipe format”, clearly base their arguments on emancipatory foundations. Consider the following:

Some people feel that not fitting in with the dominant norm and experiencing life with some sort of “difference” is in fact a great benefit, because it both releases them from the expectations of others and allows them to look at themselves in new ways.

In our culture we are bombarded with messages about who we are supposed to be, how we are supposed to act, and what our lives are supposed to mean. Therefore it's hard to separate the expectations that have been placed on us from our own feelings and needs (11).

These comments acknowledge both the social construction of internalised oppression and the freedoms that can arise from overcoming it. Even more liberatory is the book by Kroll & Klein (1992) which is less prescriptive and more inclined to lay out the options so that the reader can do what they will with them. It is based on in-depth interviews with seventy five disabled people
and offers detailed stories of their insights, experiences and problems. Instead of then listing a
guide for what to do, it lets the stories speak for themselves, unlike Kaufman et al. (2003) who
used uncited “quotes” to prove each point they were making. In essence, each of these books
and many of the others are capable of being utilised as tools of liberation because they map out
alternative “truths” and counter-narratives. At the same time, they must always be approached
with an awareness of their immersion in, and ongoing connection with, the dominant discourse.

The development of counter-narratives cannot be said to reveal the “real truth”, but they do offer
alternative truths, ‘[o]ppositional truths [which] destabilise the concept of an absolute truth by
indicating that there are other truths yet to be developed, multiple games of truths yet to be
played’ (McNay 1992: 137). It is in this way that the subjugated knowledges, both narrative and
discursive, which evolve from consciousness raising, activism and theory development can
come into play and make a difference. As Foucault (1978) argues:

… we must not imagine a world of discourse divided between accepted discourse and
excluded discourse, or between the dominant discourse and the dominated one; but as
a multiplicity of discursive elements that can come into play in various strategies …

Discourses are not once and for all subservient to power or raised up against it, any
more than silences are. We must make allowance for the complex and unstable process
whereby discourse can be both an instrument and an effect of power, but also a
hindrance, a stumbling-block, a point of resistance and a starting point for an opposing
strategy. Discourse transmits and produces power; it reinforces it, but also undermines
and exposes it, renders it fragile and makes it possible to thwart it (100-101).

Our discursive challenges, whether they exist in the form of personal narratives, critical theories
or acts of subversion, have the power to change things because they further complicate the
already multiple layers of our heterotopias and disturb what is presented by the dominant
discourse as self-evident and indisputable because it is claimed to be scientific truth or just plain
common sense.

I have argued throughout that the ability to create alternative modes of thinking and being is
always simultaneously a social and a individual process. To enable the disabled identity by
continually refusing its imputations requires that inner change is accompanied, indeed, fuelled
by an awareness of the social origins of oppression. Yet, given the necessity for structural
change and the ease by which personal endeavours can be quashed or appropriated, it often
seems that the only feasible and desirable change is overtly and collectively political. The
individual and the collective, though, are intimately connected since, as Ransom (1997) argues,
‘the disposition of forces internal to the individual [are] unavoidably central to effective action in
a broader social context’ (169). Hence:
Women did not first prepare themselves in consciousness-raising groups to effect change once outside. The consciousness-raising groups and other self-transforming practices that groups and individuals applied to themselves were the sites of change. It was in recognition of this already-achieved transformation in the subjective disposition of women that other social forms adjusted themselves. Men found themselves in relationships with suddenly different partners who were unwilling - really unable - to play the old games. Psychiatrists found their terms and criteria for defining mental health changed “from below” by patients, while official political bodies confronted a magically altered political map (Ransom 1997: 168-169).

To be able to engage in practices of liberation, it is necessary to be wary of two common forms of emancipatory promise, both of which can only serve to reinforce oppression. The first is the form of “self-esteem” steeped in neoliberal promises of independence and freedom; the second, the notion of an essentialist self which is believed to have been masked by oppressive forces and whose truth can be revealed to set one free. For reasons explained throughout this thesis, both of these will only serve to reinforce oppressive norms. In contrast, when built from a genealogical understanding or otherwise critical, socially aware perspective which acknowledges the social context in which identities are manufactured, liberatory practices are possible and hold the potential to challenge marginalisation. Hence, I believe it to be liberatory for one to cease to care about the negative attitudes of others because one understands that identity is socially constructed and that the disabled identity has grown out of negative attitudes which have a deep history. This kind of inner change stems from depersonalising the issue by contextualising it. Haber (1994) refers to this inner change as the refusal of humiliation and explains that, ‘if I don’t care about “fitting in,” then having it pointed out that I don’t will not be a cause of pain’ (86).

One can then build an identity which does not draw its meaning from a history of denigration. By recognising the points at which both the norm and the Other are constructed, one can choose alternative modes of identification which are constructed outside of both or which subvert existing categories of identification from within. Unlike the self-esteem of the psycho-sciences, the self-help movement and welfare reform with its foundations in personal reform and adjustment, the creation of a truly liberatory self-image rests upon a whole new social understanding of oppression which can be used to challenge the hegemony of the norm through activist resistance or by simply not being responsive to its prescriptions.

Many of my participants developed narratives around both forms of resistance, but Lesley Tyzack shines out as a particularly clear example of the dual possibilities inherent in the restorying process. When she found herself trapped in a nursing home in Australia with no power and no hope of escaping oppression within the existing system, she fought to return to New Zealand where she argues ‘on the whole, [they] have a much greater respect for autonomy than Australians’ (private email correspondence 2/12/01). Then, over the next twenty years she
struggled as a disability rights activist to achieve, amongst other things, the instigation of individualised care funding and the development of the necessary facilities and architectural modifications to make Canterbury University accessible to disabled people. At the same time, on a personal level, Lesley has developed an extremely positive self-definition which is resistant to the negative attitudes which once disabled her. As she was quoted as saying in Chapter Eight, ‘if someone looked at me and sort of had an unpleasant look on their face, I'd think, what's wrong with me? But now I don't ... I think, what's wrong with them? What's their problem?... I never worry about other people's opinions. I think my opinions are far more important than anyone else's’. Now she describes herself and her life as follows:

Nowadays I would describe myself as, happy, cheerful, contented, comfortable, loved, popular, motivated, busy, stress-free, optimistic, interested, interesting, intelligent, and well-informed. Perhaps it is going too far to say MS was the best thing that could happen to me, but it was certainly the making of me (email correspondence 16/11/01).

And, during one of our dialogues about the effect of negative attitudes, Lesley concluded:

... if there's one thing I can say it's that I've got good self-esteem.
CONCLUSION

I came to theory because I was hurting - the pain within me was so intense that I could not go on living. I came to theory desperate, wanting to comprehend - to grasp what was happening around and within me. Most importantly, I wanted to make the hurt go away. I saw in theory then a location for healing (hooks 1994: 59).

Above all else, my thesis attempts to map out a space in which healing can occur. Like bell hooks, I came to theory with a need to better understand my sense of erasure and to explore the possibility that my personal experience was part of something larger. My difficulty was in determining how to maintain the necessary degree of theoretical rigour while continuing to foreground the personal issues inherent in my participant's narratives and my own. Poststructural theory is based on a wariness of the personal, having declared the subject dead; grounded theorists argue that holding a strong position at the outset of a research project is antithetical to the objective of deriving theory from the data; and, until very recently, even disability studies' fundamental tenet was based on the need to extricate the individual aspects of having an impairment, declaring itself solely concerned with the structural causes of oppression.

I propose that my methodological merger has demonstrated one way of foregrounding the experiences of oppressed people within a critical framework which does not sacrifice its commitment either to theoretical rigour or to the well-being of the people it focuses upon. Fundamental to this objective has been the fact that my research contains two closely interwoven methodological intentions, firstly, that it effectively combine theory and practice in keeping with my belief that any attempt to separate them results in an artificial distillation, and, secondly, that it be "emancipatory", that is, that its primary function be to improve the conditions of the people it sets out to explore and that, accordingly, it prioritise their needs and interests.

The links between these objectives are very strong. This is partly because the practical processes involved in focusing on lived experience and attempting to transform theory into functional outcomes can sharpen theory’s liberatory edge. But, it is also because, as I have argued throughout, the application of critical social theory is a vital adjunct to the development of emancipatory strategies since it provides the means through which to contextualise individual experience by ‘deconstructing necessity’ and opening the way for alternative modes of thinking and being. Accordingly, I would like to furnish an embodiment of my reciprocal engagement with theory and practice by attempting to map out my own journey as both researcher/critical theorist and disabled person seeking emancipation.

Once I had become firm about taking a subjective position, it was obvious that this would place me in the dual role of researcher and researched. Yet, while the methodological ramifications of choosing this path seemed clear once I had worked them through, the effect of engaging in what
Miller (1991: 1) refers to as ‘an explicitly autobiographical performance within the act of criticism’ impacted upon my processes of subjectification and the theoretical insights which surround them more profoundly than I could have imagined. The insurrection of subjugated knowledges which gradually took shape through the narratives, dialogues and processes of critical analysis transformed my life by offering an infinite range of alternatives for how to think, feel and act in the world. Essentially, I am healed, and it is in this healing process, fed by both theory and practice, that I believe some very important points of reference reside.

Let me illustrate this by drawing on Boswell (2001) who claims similarly that her application of critical analysis to existing social structures enabled the construction of a new, more positive identity. She discusses the effects of her theoretical interchange with the personal aspects of disability in the following.

My awareness of my “difference” has sometimes reflected a limited self-conceptualization, where I have appropriated notions of “normalcy,” “ability,” and “power” from voices that seek to impose their world-view on me. At other times I have seen my “difference” as an entry into a range of perspectives that have situated themselves, through struggle, so as to shift discursive meaning in [such] a direction that justice, understanding, and responsibility become defining points of decision-making. Surveying a range of situations surrounding my hearing loss, I will suggest, here, that by re-weaving memories, and re-inscribing articulations which have sought to position me in limited ways, I have been able to embrace the paradox of “loss,” and to (re)construct my “disability” not only as a mark of awareness, insight, and vision, but also as a catalyst for positive change. I have come to understand that, from the very beginning, my negotiation of my (dis)ability has been closely linked to my interaction with hegemonic structures of meaning, identity, and agency (Boswell 2001: 47)

This mirrors many of my own thoughts and experiences and articulates them concisely and courageously. Boswell describes her oscillation between feeling defined by the norm and struggling to move beyond it, and claims that, ultimately, her socially located understanding of her experiences has allowed her to ‘embrace the paradox of “loss”’ and to re-contextualise disability in terms of its ability to elucidate and liberate.

I feel the same. Ultimately, my marginalised viewpoint has provided a fertile location from which to better understand the processes of subjectification affecting the lives of all people and has enabled me to exercise more agency than I was capable of accessing as an able-bodied person. Like hooks (1990a), I have discovered the power of marginality as a site of resistance. At the outset of my research, which began in 1999 when I was embarking on an honours thesis based around the notion that chronic illness is often construed in terms of moral failure, I felt isolated and confused. I was grieving because my back injury and then my viral illnesses had stolen away the life I had known. Far worse though was that my losses and limitations were often viewed in terms of individual responsibility and I felt inadequate and somehow worthless in a
variety of intangible ways. At the same time, however, I was angry at the unfairness of it all and wanted to fight it. What exactly I was going to fight and which weapons I would wield in this nameless battle were not immediately clear to me.

My undergraduate studies into the construction of knowledge had revealed the provisional and opportunistic nature of what was claimed to be “natural”, “real” and “true”, and poststructural theory offered a way of unpacking formerly unquestioned assumptions to both reveal their hidden agendas and to allow for their reconfiguration in limitless ways. Formerly, my understanding of oppression had relied on ideologies which were based on the idea of “us versus them”. In Marxism, “we” were the working class and the enemy was capitalism and in feminism “we” were women and the enemy was patriarchy. In poststructuralism I found an alternative view which problematised any claim to being a “we” and challenged the dichotomies and alternative claims to “truth” which frame traditional theories of liberation. Through my new understanding of power as diffuse I began to see that I had often participated in my own marginalisation by remaining trapped within the normative or by seeking to overcome it by simply reversing the dualisms on which it is built.

Initially, this personal relevance was partially obscured by my careful excision of myself from my research. My training in the natural sciences prevailed and I believed that it was vital to prioritise objectivity. At this stage, although I was aware that my aim to challenge structures of governance had liberatory implications, the intention of my work was not to facilitate any direct form of personal healing. However, the theoretical insights which evolved from my honours thesis and ensuing publications had a momentous impact on my world view. Fundamental to this change was the “de-personalising” of previously hurtful experiences. For example, by recognising that medical knowledge has functioned as a key mechanism which facilitates biopower’s policing of the norm, I no longer felt hurt when faced with a doctor who expressed disbelief or blame. Suddenly, I understood that this was not a personal matter in which I had been specifically judged as culpable. Rather, when taking into consideration the history of thought governing the practice of medicine, any other reaction seemed rather unlikely.

A more general, cross-cultural understanding of the history of illness as “sin” helped me to recognise that human beings have tended to comfort themselves in the face of uncertainty by believing that they can control their lives and that the world is essentially just. Once again, my understanding of why people often seek to assign blame for blameless events made this kind of response seem inevitable rather than a specifically targeted indictment. Thus, as I became increasingly aware of the liberatory power of critically contextualising personal experience, the idea began to take form that I should bring the personal and the theoretical together in one piece of research.
The emancipatory potential of this fusion has been evident at every level. Most fundamentally, the stories have been illustrative and illuminating and have provided a great deal of insight into how the norm is either adhered to or challenged. The authors of the published works and those participants who wrote their stories commonly referred to their writing in terms of healing and catharsis. The dialogues involved a similar process and included an extra layer of narrative building and the potential for healing based on the intimate and reciprocal nature of shared experience. Many of my participants claimed that the dialogues were helpful either because they allowed them vent or because new insights arose from them. It was I who benefited most of all, however, because I participated in all of the dialogues and read all of the autobiographies and participant contributions. Some of the revelations I had while talking to or reading about these innovative and courageous people have had a monumental impact on my life, such that my narrative has continued to change and has required perpetual reinscription as a result.

When I began my project I was defined by feelings of loss and shame. Now, like Boswell and hooks, I see my marginalisation as a position of strength and insight. This has involved a process of subversion, as opposed to the creation of a “triumph narrative”, and, as such, can be understood as a kind of “becoming” which has been fed by the development of the sociological insights which frame and evolve from my research. When I say that I have been healed I mean many things, but the healing which seems to infuse every layer of my existence is that which has arisen from my burgeoning ability to dissociate myself from the negative attitudes of others. I understood right from the beginning that my identity relied far too heavily on external sources and my investigation into the construction of disability and identity helped me to understand why this was so. However, although this genealogical interpretation cultivated the soil in which I could conceivably plant the seeds of a new set of self-perceptions and I found some degree of comfort in contextualising unkindness and the manifestations of my ailing self-esteem, I still found it hard to shrug off my shame in the face of other people’s pity, aversion, ostracism or condemnation.

This tended to play itself out in ways that one of my participants, Lee Trustrum, empathised with and referred to in terms of ‘the shame of being ashamed’. For, if I understood the social roots of the attitudes which gave disability its negative slant, why was I still largely trapped within them? It made me feel silly that I still cared so much about how others viewed me, particularly when they were strangers. My eventual revelation in this regard was built from a variety of sources over time, but there was a pivotal moment during which I experienced a leap in understanding and, from that time onwards, I have moved in the world in a far more comfortable and less externally-defined way. During one of our dialogues, Lesley Tyzack and I were discussing this issue and I was taking the opportunity to explore why I had still been unable to completely dissociate myself from negative reactions. I shared my concern that, to stop caring, I risked becoming insensitive to the feelings and needs of others and Lesley replied, ‘Yes, well, I try to consider other people's feelings, but it's just their opinions that I don't allow to influence me’.
What happened during and after that conversation was based on a coming together of the subjugated knowledges which stemmed from my prior genealogical understandings, the generation of insights that evolved from narrative, dialogue and role modelling, and their consequent re-contextualisation through theory. Understanding where negative attitudes emanate from historically was the first big step toward letting them go, but my readings from and conversations with disabled people often provided the final layer of insight necessary to fully apply the deconstruction of necessity to daily life. In this case, the disentanglement of people’s opinions from their feelings was the key I had needed to enable the release of my self-perceptions from what were formerly hurtful attitudes and behaviours. Indeed, what was once painful became interesting or, if subtle, remained beneath my level of awareness. Like Lesley, I no longer think “what’s wrong with me?”, but, instead, I am able to contextualise the attitudes and behaviour of others and, as a result, can be compassionate, unconcerned or even, at times, amused.

During another dialogue with Lesley I said that I admired her and felt she was a lot stronger and more insightful than I was. She replied ‘You must remember it’s been going on a long time for me. It was 1980 that I had the first bad attack of MS and, I mean, that’s twenty two years now. It’s a long time to come to terms with it’. This reinforced my growing awareness that disability involves a trajectory and that, when one person is further along in their trajectory than another, they can act as role model and mentor. Many of my participants, particularly Lesley and Chris, have performed this function for me in a way that theory alone could never have achieved.

However, this does not negate the vital role performed by theoretical insight in the emancipatory process. The weaving together of critical analysis and lived experience occurs, not only on the ground when negotiating and challenging the disabling of identity in a practical sense, but in the development of new theoretical conceptions within the academy. My thesis has grown from the constant attempt to keep theory and practice closely intertwined. This confluence reached its culmination during the final layer of analysis in Chapter Ten when the insights which emerged from the application of governmentality to the narratives were fed through a new organising structure based on the concepts of self-esteem and empowerment. At this point, I experienced the way in which the act of writing – writing as theoretical praxis – makes possible a leap into previously unimagined territory. Writing provides yet another means for drawing theory from data, whether that “data” be textual or narrative or, as in my case, a combination of both.

Indeed, as Cixous (1980) suggests, ‘writing is precisely the very possibility of change, the space that can serve as a springboard for subversive thought, the precursory movement of a transformation of social and cultural structures’ (149). As Merleau Ponty (1962a: 46) points out, by attempting to express the inexpressible, we uncover the gaps or ‘the threads of silence that speech is mixed together with’ and, thus, enable the development of ‘truly expressive speech’.
This kind of writing is not simply a mechanism for reporting insights already derived from analysis. It involves new levels of connection and creation in the melding of theory and practice. In my case, this produced a further leap in how I understand my own subjectification and its potential for subversion, and I also believe, as Cixous (1980) argues in relation to the writings of the marginalised in general, that this kind of combination of theory and practice through the act of writing opens the way for ‘a mutation in human relations, in thought, in all praxis … [a] staggering alteration in power relations and in the production of individualities’ (253).

As a result, I am now much clearer about how to exercise agency in the ongoing process of building and maintaining a desirable identity. I can read a self-help book or engage in welfare reform practices with an awareness of what is embedded in neoliberal, individualistic processes of self-actualisation and what may be utilised in emancipatory ways. Accordingly, my sexuality is no longer a site of grief and abjection, both because I no longer see it as a primary mode of identification and because my readings have opened up new possibilities in relation to sharing pleasure and exploring desire in keeping with a body which continues to shut down, piece by piece. And I am now at the point where I have recontextualised my understanding of “work” and I no longer need an occupational identity to shore up a troubled self-esteem. It seems paradoxical on one level, but inevitable on another, that my very fulfilling and pride-inducing work in the world of academia has culminated in the knowledge that my identity is no longer reliant on my participation in paid employment at all.

Herein lies the essential difference between a “triumph narrative” and one based on emancipatory insight. I struggled with this distinction when I was about half way through my dissertation. Being on scholarship, winning a bursary, and achieving publication helped me to feel better about myself than I had felt since becoming disabled. Yet, it was possible that I was merely participating in the formation of a triumph narrative which may be construed as supporting the view that all people can overcome their limitations if only they try hard enough and may tie me inexorably to the ongoing need for such achievements. Once again, however, the ability to contextualise these kinds of experience served to uproot them from their normative foundations and I am now confident that my identity will remain comfortable regardless of whether I can work or not. This is an enormous relief to me for, although I once relied heavily on being able to continue my academic work, it appears that the recent acceleration of my failing health may preclude this possibility. In the end, disability has granted me an escape from the tyranny of the norm.

To describe one’s own autobiographical experiences in relation to their theoretical development requires a genealogy of its own. Ribbens (1996) writes of the ‘taken for granted … psychic embedded ness’ of autobiographical accounts, conceptualisations which I believe must be challenged if we are to ‘encourage academic sociology to reflect upon itself and provide more space’ for the development of such accounts (91). In other words, because it is often assumed
that autobiography is personal and unique to the individual, we can have trouble accessing its social meaning. This, I suggest, can only serve to stifle sociological insight and emancipatory thought, with the exclusion of the personal from the theoretical functioning as just one more form of silencing. Yet, as Merton (1988) argues, sociological autobiography is of prime theoretical relevance because it involves ‘the interplay between one’s sequences of status-sets and role-sets on the one hand and one’s intellectual development on the other, with its succession of theoretical commitments, foci of scientific attention, planned or serendipitous choices of problems and choices of strategic research sites for their investigation’ (19).

It is in this interplay between personal experiences and intellectual development that the reciprocal engagement between theory and practice occurs. They only appear as two dissociable processes or sites of change when mapped out in two dimensions in the attempt to better understand them. In practice, these processes occur simultaneously and constantly feed into one another, and, once again, it is in writing about them that new insights about their interaction can develop. This is particularly the case when the theory springs from the genealogical analysis of subjective experience. As Couzens Hoy (1998) argues, that because genealogy shows that self-understandings are not only interpretations, but contingent interpretations with the possibility of subversion, ‘politics and philosophy are no longer entirely irrelevant to each other, but instead, they become mutually reinforcing activities’ (30-31). The aim here is not to pretend that one person’s experiences mirror those of all people or that one solution fits all situations, but to demonstrate how the historical and the biographical interrelate and to provide examples of how an individual’s involvement with genealogical insights can instigate a process of positive change through opening up new possibilities. My story is not definitive, nor are any of the other narratives represented here. But, it is hoped they can provide stepping stones, signposts or springboards in the journey prompted either by the experience of marginalisation or the tyranny of almost, but never quite, approximating the norm, and, as such, become ‘instruments and tools that people might find useful’ (Foucault 1988c:197).

As such, my thesis may be seen to map out part of a journey based on beginnings initiated long before its birth. It leads towards, not concrete outcomes, but multifarious possibilities which continue to change shape as quickly as they appear solid enough to fully grasp. It is not so much the nature of change which is the issue here, but the simple, yet complex recognition that change is possible at all, at every level and in every situation. By understanding the historical immersion of our identities in value-laden dichotomies which stem from the very basis of language itself, we can begin to chart new ways of thinking, acting and speaking which can serve to restructure power relations and generate multiple points of resistance. And by utilising disability as a critical modality for understanding the distinction between the affiliated and the marginalised and revealing how both suffer from its specifications, it is possible to begin to see difference as exciting and inevitable rather than in terms of mutually exclusive extremes. When seen in this way, identity can celebrate its chameleon possibilities while retaining its power to
represent a coherent and desirable way to shape the process of “being”, leaving the disabled identity as a social location which can be unmade, shrugged off, left behind.
APPENDIX ONE

Participant Descriptions*

Aaron
Aaron is a 32-year-old man who lives in the ACT, Australia. He gradually became profoundly blind after developing a vision impairment at age 7. He speaks in strong terms about the discrimination he has faced in the education system and employment and is currently engaged in building a case for the attention of the Human Rights Commission in relation to workplace discrimination.

Adrienne
Adrienne is a 52-year-old Jewish woman who lives in the USA. She developed chronic fatigue syndrome (CFS) 12 years ago, gradually had to give up work in her positions of paid employment and, over time, has become active in the disability rights movement, particularly in relation to transport accessibility issues as she uses a wheelchair.

Amanda
Amanda is a 21-year-old woman who lives in Northern Territory, Australia. She developed CFS two years ago and is still coming to terms with having to drop out of university in her first year. She still hopes to return to her studies and is very distressed at having to be dependent on her parents after having left home at 16.

Angus
Angus is a 52-year-old man who lives in NSW, Australia. He has a range of chronic illnesses, many of which are yet to be satisfactorily diagnosed. Angus became ill ten years ago and this has greatly affected his life and his ability to work. He is still employed but lives with a constant fear that his failing health will eventually prevent him from continuing to work.

Anne
Anne is a 43-year-old woman, originally from Croatia, who lives in NSW, Australia. She injured her foot ten years ago and tried to keep working but eventually had to give up. Other than the loss of her career, Anne’s greatest sense of loss revolves around the ability to effectively parent her child who was an infant at the time of the onset of her impairment.

Celia
Celia lives in South Australia and describes herself as ‘a 43 year old mother of three’. After recovering from cervical cancer and tuberculosis in her early twenties, Celia developed Chronic

* Current at time of dialogue in 2002.
Fatigue Immune Deficiency Syndrome (CFIDS) at age 28. Added to her fatigue, she suffers from an extreme sensitivity to chemicals, a condition which isolates her in the attempt to avoid debilitating exposure to chemicals that most people take for granted such as perfume, hairspray, household cleaning products, petrol and fresh paint. She is devastated by her ongoing illness, but felt that being able to share her story with me helped to lighten the load.

Chris Baker
Chris is a 54 year old New Zealand man whose mixed Samoan and Irish heritage locates him in a bicultural position which has provided a great deal of insight into the identity issues which are common to disability. He began to develop the symptoms of Multiple Sclerosis 12 years ago is now living in a nursing home. He remains a prolific writer whose work continues to be published. Some of his more recent stories are being produced as radio plays for Radio NZ and in 2004 he began attending university to obtain a Communications degree. His resolution of his initial identity problems can only be described as profound.

Craig
Craig is a 50-year-old man who lives in New Zealand. He became completely blind due to an accident when he was 18. Craig was originally institutionalised and was given work in a sheltered workshop, but gradually managed to move back into the mainstream. He has a happy marriage and family life, a challenging career in the ministry, and, now that his children have grown up, he and his wife travel extensively.

Dianne
Dianne is a 60-year-old woman who lives in London. She first developed symptoms of Multiple Sclerosis 30 years ago. This eventually stopped her from working and resulted in her need to use a wheelchair. She is married to a supportive partner, has children, and has become extremely active in the community in ways that she feels has given her an extremely positive identity.

Frank
Frank is a 58-year-old man who lives in NSW, Australia. He developed chronic fatigue 30 years ago from a series of liver debilitating viruses. He continued to attempt to work, finding each time that it made him ill for months afterwards. He eventually accepted a disability support pension, but is still finding it hard to establish how much he can do in a physical sense without damaging his health. He appears to have no identity issues at all because he has always felt that the norm should be challenged and so he sees himself and his life in subversive terms.

Glen
Glen is a 62-year-old man who emigrated from England to Australia ten years after becoming disabled at the age of 19. He was involved in a motorbike accident, which resulted in a
tragic brain injury and extensive paralysis. His main concerns relating to disability have been his limited options for employment and the lack of assistance he has received in relation to dealing with his daily needs and his emotional problems.

Greg
Greg is a 65-year-old Australian man who began to develop a vision impairment at the age of seven. His failing eyesight caused him a great deal of distress during his school years and made him feel “inferior” and that he was continually treated as “naughty”. He later did exceptionally well at adult education, built a happy marriage and feels very positively about himself and his life.

Jack
Jack is a 42-year-old man who lives in Queensland, Australia. Five years ago he developed a chronic pain disorder, which stopped him from being able to work and is threatening to destroy his marriage. His greatest identity issues are related to his loss of occupational identity and the negative attitudes of those around him who think he is lazy.

Jacky
Jacky is a 34-year-old woman who is studying for her PhD in psychology in New Zealand. She was involved in an accident 8 years ago which resulted in a traumatic brain injury and led to the loss of her career at the time. She hated being on welfare and felt that people were very discriminatory in general and now feels that a social model perspective gives her a way of combating the negative stereotypes.

Jane
Jane is a 25-year-old Australian woman who developed Chronic Fatigue Syndrome at the age of 19 while she was studying drama at university and working part time to support herself. She, like Adrienne and many of the others with CFS, felt that her extreme workload contributed to the development of her illness. Her greatest sense of loss has been in relation to her independence as she has had to move back to her family home to be cared for by her mother.

Janet
Janet is a 28-year-old English woman who is now living in New Zealand. She was born blind but is adamant that this had no bearing on her identity at all. Her problems with disability arose five years ago when a car accident caused her to sustain a head injury, liver damage and ongoing, severe abdominal pain. What appears to be most upsetting to Jane is that head injuries are so poorly understood. They are not looked at as physical injuries or physical disabilities but as

*In this case and in others where I felt that I may be able to link up my participants to relevant community supports I attempted to do so (with varying levels of success due to the constant erosion of government funding in Australia).*
connected to the realm of mental health problems and she believes that this is an area that people are very uncomfortable with and very ill informed about.

Jeanette
Jeanette is a 29-year-old PhD student who lives in the USA. She developed Crohn’s Disease at age 12. Throughout her life she has largely kept her condition hidden and has only just started to “come out” to her students in the disability studies class she is teaching. She takes a social model perspective to disability and is dedicated to helping young Crohn’s sufferers to develop positive identities.

Karen
Karen is a 38-year-old New Zealand woman who was born with paraplegia due to a genetic condition. She did not experience any identity problems until she began to take an interest in boys in her late teens and realised that her options would be limited by her disability. She was not offered the government assistance to live independently given to accident victims because she was born with her impairment, so she had to fight for many years to obtain the assistance provided by the Accident Compensation Corporation. Karen now works in a challenging job, is active in the Disabled People’s Assembly and is happily married.

Lee Trustrum
Lee is a 52-year-old New Zealand woman who has a genetic neurological disorder which has given her mobility problems from birth. She says that her impairment is largely invisible to the rest of the world, yet her physical difference and its genetic links to other family members with the same impairment has continued to make her feel inferior and somewhat ashamed.

Lesley Tyzack
Lesley is a 54-year-old New Zealand woman who was born in England and spent many years living in Australia. She developed Multiple Sclerosis 22 years ago and quickly developed quadriplegia which resulted in repeated institutionalisation in nursing homes in Australia. Once she was able to get to New Zealand, where she had first been married and where her children resided, she was able to obtain access to the kinds of supports which have allowed her to develop an autonomous, fulfilling life. She is president of the Christchurch branch of the Disabled People’s Assembly, a member of Toastmasters, has just graduated from a psychology degree and is currently writing both fiction and an autobiographical treatise designed to help people who are experiencing the early stages of MS.
Luke
Luke is a 63-year-old man who lives in Western Australia. He developed paraplegia when he was involved in an accident at work 30 years ago. He is a very positive person and reports no identity problems at all. He felt that his accident led him to get involved in a new career and that he had completely triumphed over adversity. His story was reported on a television show which portrayed him as a disabled hero. He is extremely cheerful and philosophical, but does not reflect on this being part of a transition.

Michael
Michael is a 56-year-old man who lives in the USA. He was supporting himself by writing novels until he developed CFS and fibromyalgia 8 years ago. He is very angry that his ability to think clearly has been so severely compromised and discusses identity in terms of his impaired cognitive ability (known as “brain fog”) and extreme fatigue. He is now in receipt of welfare assistance and finds the whole process extremely demoralising.

Monique
Monique is a 22-year-old woman who lives in Perth, Western Australia. She was pursuing a very successful career as a dancer when she developed CFS three years ago in response to a run of viral infections. She says now that she had defined herself almost solely in relation to her dancing and has had to restructure how she sees herself. And, like Jane, Monique feels uncomfortable about being dependent on her parents.

Nancy
Nancy is a 68-year-old woman who became institutionalised in New Zealand after experiencing a Spinal Cord Injury due to a fall when she was thirty years old. She tells a very powerful story of fighting against the discriminatory treatment she received in the early days and how she developed an autonomous life through writing and studying and becoming involved in the Disabled People’s Assembly.

Neil
Neil is a 52-year-old Australian man who sustained a traumatic brain injury due to a car accident 8 years ago. He has worked extremely hard to regain some of the physical independence he had lost due to his substantial paralysis and is very keen to contribute to the community in any way he can. Consequently, he works in a voluntary capacity for a number of different organisations and is a very clear example of the “active neoliberal citizen” discussed in Chapter Nine.

Paul
Paul is a 47-year-old man who lives in NSW, Australia. He says his vision was always somewhat impaired due to a premature birth, but that he ultimately became legally blind at age
30. He originally resisted acknowledging his problem until he almost had a head on car accident. After that he gave up driving and eventually lost his ability to work. He says that his marriage broke up because he was a “workaholic” and that, since then, he has not been able to meet another partner because his blindness causes such severe problems with socialising. He tells a great many jokes and makes light of things, but is obviously disappointed with how his life has turned out due to his blindness.

Peta
Peta is a 26-year-old PhD student who lives in London. When she was 12 she developed a visual impairment which ultimately led to blindness. Her greatest identity issues have revolved around the negative attitudes of others, something which she’s been able to resolve by understanding disability as a matter of social exclusion. She says that she didn’t consider herself as disabled until she came to see disability as a social construction and she now feels that affiliating herself with other disabled people is part of an extremely emancipatory process.

Rita
Rita is a 53-year-old woman who lives in NSW, Australia. She developed CFS five years ago and has lost her ability to engage in any of her usual household tasks. She feels very depressed that she has to rely on her husband for everything and demoralised that her 8-year-old child thinks of her as lazy.

Robert
Robert is a 49-year-old Australian man living in NSW. He has developed a range of chronic illnesses and impairments over the past ten years which have made it very difficult for him to work. He is extremely proud of his ability to continue working despite his physical problems and he speaks strongly of the need for stoicism.

Stan
Stan is a 64-year-old New Zealand man who began to develop Multiple Sclerosis at age 32. Although he soon needed to use a wheelchair, he did not have to give up work and he continued to travel extensively, including a trip he won as a result of gaining a Churchill Research Fellowship. He is a disability rights activist and focuses on issues of increasing access in relation to transport and buildings.

Susan
Susan is a 42-year-old PhD student who lives in the south west of England. She first began to develop the symptoms of Multiple Sclerosis 8 years ago and now uses a stick and a scooter to aid in her mobility. She feels driven to work harder than most people to prove her capabilities and has taken on a social model perspective to better understand her marginalisation and how to overcome it.
**Tanya**
Tanya is a 32-year-old woman from Victoria, Australia who developed CFS six years ago. She lost her marriage and her ability to work and feels incapable of rebuilding her life when she has barely enough energy to get dressed in the morning. She is beginning to question her process of self-definition and to challenge the normative prescriptions which have made her feel worthless because of the loss of her occupational identity, independence and active citizenship.

**Terry**
Terry is a 42-year-old Australian man who moved to New Zealand five years ago. He became profoundly blind in an instant due to a car accident 14 years ago. He still talks sadly about the loss of his career, but jokingly talks about everything else relating to disability.

**Wally**
Wally is a 22 year old man who lives in NSW, Australia. He became blind in a work-related accident 5 years ago and feels that he has not been adversely affected by his impairment. He makes a joke about the whole thing and says that it has made him a better person.
APPENDIX TWO

Variation in Attributes Represented in Sample

- Time since onset of impairment.
- Nature of condition, e.g. stable, fluctuating or periodic.
- Incidence and level of pain.
- Affect on cognitive ability.
- Type of support available, e.g. family members, friends, professionals etc.
- Degree of validation in relation to diagnosis.
- Place of residence, e.g. own home, parents’ home, institution.
- Presence of illness.
- Employment status.
- Source of income, e.g. occupational, welfare, compensation, family.
- Ability to walk.
- Level of self-reliance.
- Relationship status and how disability affected it, e.g. married before or after onset of impairment, loss of relationship due to impairment, loss of ability to develop relationship.
- Nature of onset, e.g. gradual or sudden.
- Visibility of impairment and, if “invisible”, the tendency to “pass”.
- Age.
- Level of education.
• Ethnicity.
• Location.
• Access to resources.
• Involvement in disability politics/activism.
• Tendency to refer to oneself as disabled.
• Adoption of social model.
APPENDIX THREE

Consent Form
Division of Social Sciences, Humanities and Education
School of Social Inquiry

Consent form for participation in the research
conducted by Rose Galvin
and referred to as:

Disability as a Challenged Identity

I am a PhD student at Murdoch University investigating the effects that disability has on identity. The purpose of this study is to find out how disability changes both the way people feel about themselves and how other people view them. It is hoped that the results of this research will lead to a better understanding of how disability affects self-image so that negative feelings can be challenged and changed.

You can help in this study by consenting to one or more interviews. It is anticipated that the time to complete the first interview will take no more than one hour, and, if both parties agree, further interviews may be arranged. Contained in the interview are questions about the experience of illness and disability and other questions which may be seen as personal and private. Participants can decide to withdraw their consent at any time. All information given during the survey is confidential and no names or other information that might identify you will be used in any publication arising from the research. Feedback on the study will be provided to participants.

If you are willing to participate in this study, could you please complete the details below. If you have any questions about this project please feel free to contact either myself, Rose Galvin, on 0266548256 or my supervisor, Dr Trish Harris, on 08 9360 2252.

My supervisor and I are happy to discuss with you any concerns you may have on how this study has been conducted, or alternatively you can contact Murdoch University's Human Research Ethics Committee on 08 9360 6677.

************************************************
I (the participant) have read the information above. Any questions I have asked have been answered to my satisfaction. I agree to take part in this activity, however, I know that I may change my mind and stop at any time.

I understand that all information provided is treated as confidential and will not be released by the investigator unless required to do so by law.

I agree for this interview to be taped.

I agree that research data gathered for this study may be published provided my name or other information which might identify me is not used.

By returning this completed form by email the applicant consents to the above conditions.

Participant/Authorised Representative:

Date:

Researcher:

Date:
APPENDIX FOUR

List of Autobiographies and Anthology Contributions


APPENDIX FIVE

Annotated Bibliography of Sexual Rehabilitation Texts

1) Texts aimed at educating health professionals


This is a compendium which is written by doctors to educate doctors in the matter of incorporating sexual guidance in their caregiving role in relation to disabled people. Some chapters deal with general issues surrounding disability and sexuality, but most deal with specific impairments and focus heavily on physiology and its bearing on psychoanalytical issues, often referring to psychosomatic problems.


This is a very short and simple guide written by a consultant advisor on sexuality issues and a family planning counsellor with the aim of educating health professionals such as doctors and nurses in general practice and family planning counsellors, physiotherapists, occupational therapists, health visitors and social workers. It makes brief mention of emotional issues, but focuses mainly on anatomical issues and practical concerns such as contraception.


Written by a GP who is also a marriage guidance counsellor and a member of the committee on Sexual Problems of the Disabled and aimed at those who care for disabled people. It is mainly focused on those who live in institutions and rests heavily on a normalisation theme. It is based on a pity model rather than one which promises to empower.


A compilation written by social workers and those who research in the area of social work, aimed at educating social workers in the belief that they are placed in many areas, both institutional and in the community, where sexual counselling would be helpful to disabled people. It describes various training programmes that could be developed to serve this purpose.
and focuses on some special problem areas such as sexual abuse and intellectual disabilities (referred to as mental retardation).


The authors are occupational therapists and they direct their book at the training of rehabilitation professionals in general, the aim being to educate them in the basics of sex counselling with disabled people.


This text is written by a psychiatrist and a psychologist and aims to educate doctors, mental health professionals, nurses, occupational therapists and physical therapists. It argues against a purely biological approach and advocates a psychosocial perspective. Rather than getting away from the medical model, however, it constructs disabled people’s sexuality in terms of psychological problems rather than biological ones.


The editor of this comprehensive compendium describes himself as a “sexologist” and the authors largely come from a psychology background. It is their aim to provide a text which will help rehabilitation practitioners to counsel and educate their disabled clients. It is based on a very strong medical model view and relies heavily on quantitative research methodology.


The book is a dense and comprehensive text edited by a doctor and a psychologist. It covers the physical and psychological impact of disability on sexuality and traces the various laboratory tests and treatment programmes that are available. It is a very strong example of the medical model approach.
2) Self-help literature


Deborah Kahane is a cancer survivor and social worker who aims to combine her experiences in both areas with the objective of filling the need for ‘psychosocial and sexual information’ relevant to the experience of breast cancer and mastectomy. The first half of the book presents the stories of women with breast cancer in which they discuss the effects of their cancer experience on their self esteem, while the second half draws from the stories the main themes which the author believes demonstrates why these women have such a strong sense of self esteem despite the challenges they faced.


This book is written by a sex toy retailer, a disabled women who trains and educates service providers in the issues sexuality and disability, and an educator in the field of adolescent medicine. They certainly have an emancipatory view on sex and disability and are very keen to challenge normative boundaries, yet, at the same time, the format of the book is very prescriptive, structured in the form of a recipe or set of guidelines and it is heavily laced with self-actualising language and concepts.


This book is a self-help book in that it is a “guide” but, unlike Kaufman et al. (2003) it is less prescriptive and more inclined to lay out the options so that the reader can do what they will with them. It is based on in-depth interviews with 75 disabled people and offers detailed stories of their insights, experiences and problems. Instead of then listing a guide for what to do, it lets the stories speak for themselves, unlike Kaufman et al. (2003) who used uncited “quotes” to prove each point they were making. Each book is valuable in its way, but this one appears to be far more emancipatory in a poststructural sense because it avoids peddling “truths” and allows for infinite ways to view disabled sexuality.
3) Borderline between expert texts and self-help


This startling book was put together by three doctors who specialise in the field of human sexuality. They aim it at both disabled people and the rehabilitation professionals who work with them. It is based on the belief that people who have spinal cord injuries have the right to free sexual expression but that they have been denied the information and resources with which they can pursue this right. It is filled with extremely explicit photographs of the issues that face people with SCIs when they approach sexual situations such as how to deal with catheters, poor bladder and bowel control and which positions facilitate different functional limitations.


This book is written by someone qualified in the area of social work who aims to bring the information which has been developed by doctors and psychologists in relation to disability and sexuality into an accessible form for those whose impairments have affected their sexuality. It obviously draws on the medical model research into the physical and psychological effects of disability on sexuality and presents it in a clear and sensitive manner. I place it in the borderline category of texts because it does not follow a self-help, recipe-driven format. It is more like the texts directed at experts, but the language is more accessible and it is directed at disabled people themselves.
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