If I Only Had a Brain

Deconstructing Brain Injury

Mark Sherry

NEW APPROACHES IN SOCIOLOGY
STUDIES IN SOCIAL INEQUALITY, SOCIAL CHANGE, AND SOCIAL JUSTICE

Edited by
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Chapter One

Introduction

This book began, as most do, with a personal experience. I was crossing the road and was run over. Seriously injured and not expected to live, I began my recovery from my life's most unexpected and traumatic twist. My brain and body was a mess; I had operations for the next 9 years. In one sense, this book is about one of my injuries—a brain injury. But it is really about far more than that. It is about identities, disability, difference, the public and the private, human variation, and about the complex interaction of biological and social forces. It is about power and oppression, and how people are situated in a complex web of interlocking social positions which rarely makes them a "pure" victim or a "pure" oppressor. My journey back from near death has been well documented, through many news stories in my home country Australia, and I gained a tiny degree of fame through this experience. I soon found myself positioned as a disability rights advocate and hundreds of brain injury survivors around the world began to contact me, sharing their stories, asking about my recovery, and looking for answers. I was asked to write about the collective experiences of people who were in rehabilitation with me, and have written this book in the desire to capture some sense of these people, their dreams and aspirations.

Brain injury involves so many elements, it is difficult to know where to begin. Should I start by talking about what it is like to suddenly and unexpectedly become disabled? Or should I begin by discussing the causes of brain injury, such as the domestic violence that leads to so many brain injuries among battered women and children? What about the difficulties that so many people experience with the activities of daily living—how much emphasis should I put on that? Perhaps I should talk about the way some people are misdiagnosed, labeled as "vegetative" and left for years in nursing homes without proper rehabilitation? And the high levels of brain injury among ethnic minorities and poor people—how can I draw that to people's attention?

I struggled with these questions for a long time. In the end, I adopted an interdisciplinary approach to the topic. In order to explain what it is like to be disabled, I drew on the disability studies literature. And in order to understand the mechanics of brain injury, I drew upon the medical literature. However, I felt that these two approaches alone would leave my project seriously incomplete. I wanted to expand its scope. Taking inspiration from feminist literature, I wanted to be sure to include the public and the private. I wanted to highlight the sexual dimensions of brain injury, and the effects that brain injury has on intimate relationships. I also wanted to recognize that men and women with brain injuries often have radically different experiences. And when I thought about the uneven distribution of brain injury in the community (certain racial and ethnic groups experience a much higher incidence of brain injury than others), I wanted to examine these dynamics as well. This interest eventually led me to the literature about postcolonialism, which seeks to explain the historical and continuing effects of racism and imperialism among different racial groups.

It should be clear that this is not a regurgitation of the traditional rehabilitation approach to brain injury. There are plenty of books on that subject, and many authors who are far more qualified to speak about it than I am. Instead, in this book I am trying to write a cultural analysis of brain injury, which draws upon the knowledge of people who have experienced brain injuries in order to see what they can teach us all about identity, disability, our sense of self, and our relationships with the world. The approach I have taken towards brain injury has been deeply influenced by the wider literature on disability studies. Linton (1998a:2) defines disability studies in the following way:

> Disability studies takes for its subject matter not simply the variations that exist in human behaviour, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of these variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state.

Disability studies has been embraced by many disabled people because of the way it draws upon their experiences and emphasizes society's failure to accommodate their needs. It also challenges the medicalization of disability and critically examines society's response to an individual's impairment.

One of the more controversial aspects of my language around disability is the conscious use of the phrase "disabled people" ahead of "people with disabilities." I am one of a minority of people who prefer this term—in Australia at least. I know that it is very popular in Britain. The reason why "people with disabilities" is popular is because it suggests that people with disabilities are people first, and their "disabilities" come second. The criticism of this argument from disability scholars, however, is that to accept being a "person with a disability" is to accept conditional humanity: granted personhood on condition that they act as a "normal" person, albeit with an impairment (Michalko, 2002). An alternative terminology, which particularly holds sway in British disability literature, is to refer to "disabled people." It is suggested that this terminology highlights the oppression experienced in a disabling environment (Morris, 1993). This argument relies on the distinction between "impairment" (bodily difference) and "disability" (prejudicial social reactions to that difference). Among the most progressive elements of the disability movement, "disabled people" is clearly the preferred terminology and I have chosen to use it in this book. However, I also want to register my unease with certain sections of the disability movement who actively police the use of these terms and who are intolerant of others who occasionally use uncommon language. I have wept when I have seen my own work changed, without my consent, so that it conformed to the editorial guidelines of certain disability magazines. For instance, I was asked to write an article on disability hate crimes by the Australian disability publication, Link magazine, only to see my language changed to fit their preference of "people with disabilities" (Sherry, 2003). I simply want to acknowledge that language around disability is always contested and that there are many positions, both within and outside the movement, on this issue. My use of a language which is preferred only by a minority is meant to be deliberately oppositional, in order to promote tolerance of a plurality of viewpoints.

Disability means various things to various people. Legislative definitions of disability have become increasingly important in the context of commodified welfare assistance to disabled people and accordingly have been subject to a great deal of attention and review (for instance, Albrecht, 1992; Albrecht and Levy 1981; Hahn 1986; Pedlar and Hutchison 2000; Priestley, 1999; Stone, 1984). Indeed, these definitions have changed so often that Hahn (1985: 294) said "Fundamentally, disability is defined by public policy. In other words, disability is whatever policy says it is." Particularly in North American disability studies, disability is often defined by contrasting it to "normality" (Davis, 1995; Russell, 1998; Thomson, 1997a). For instance Davis (1995) argues that social relations which highlight and devalue bodily difference consolidate the "hegemony of normalcy." He reconstructs disability not as an object of the body but as part of a hegemonic way of thinking about the body and its role in the body politic. The state of "disability," like that of "normalcy," is therefore a reflection of biopower. Indeed, Davis believes a "somatic judicial system" enforces the hegemony of normalcy, marginalizing any departure from the goal of a seamless, whole, complete and unfragmented body. Davis (1995: xii) argues that the goal of disability activists has often been "to help 'normal' people to see the quotation marks around their assumed state." Shakespeare (1996: 96) makes a similar point when he comments: "a situation where disabled people are defined by their physicality can only be sustained in a situation where non-disabled people have denied their own physicality."

The problem with defining disabled people by referring to conceptions of normality is that the disadvantages experienced by people who are labeled "abnormal" do not derive from biology but from implicit social judgments made about certain forms of human variation (Amundson, 2000). So rather than contrast "disability" and "normality," as many American disability scholars do, I have tended to follow the British model which attaches a more technical meaning attributed to "disability." In this British literature, the terms "impairment" and "disability" are used fairly consistently: "impairment" is the term used to refer to medical conditions and "disability" refers to the social reactions to impairment, particularly experiences of discrimination, oppression, social exclusion and marginalization (for instance, Abberley, 1999; Ahmad, 2000; Barnes, 1999; Drake, 1999; Marks 1999; Oliver 1996; Oliver and Barnes 1998; Priestley 1999). By recognizing disability as a set of power relationships involving exclusion and marginalization, disability studies makes a parallel with other forms of oppression such as racism and sexism.

Beckett and Wrighton (2000), Garland-Thomson (1997a) and Wendell (1996) are among many scholars who explicitly compare the social construction of gender with the social construction of disability. Both feminism and disability studies focus on people who have been categorised as the "Other." They both challenge the public/private divide which locates personal experiences of oppression in the private sphere. Rosemary Garland-Thomson (1997a: 22) has highlighted the similarities between the social meaning assigned to disabled and female bodies:

> I want to theorize disability in the ways that feminism has theorized gender. Both feminism and my analysis of disability 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 universalizing

> norms; both interrogate the politics of appearance; both explore the politics of naming; both forge positive identities.

The feminist strategy of distinguishing sex from gender has been a conceptual framework which parallels, and perhaps inspired, the distinction in disability studies between impairment and disability. In the same way that feminist politics has challenged the idea that being biologically female destines a woman to domesticity, child care and passivity, the impairment/disability divide contests the construction of disabled people as passive, helpless and needy.

Garland-Thomson suggests that feminism has considered these issues far more than disability studies. However, it is difficult to speak of the disability movement and the feminist movement as separate entities, since many disabled people are feminists, and many feminists are disability rights activists. Feminism has greatly influenced the political analyses and tactics of the disability movement, though the extent to which feminism has changed to accommodate the needs of women is open to debate. Meekosha (1990) argues that changes within feminism in response to the demands of disabled women have often been little more than rhetorical. Nevertheless political struggles of disabled people have frequently taken inspiration from the feminist movement. For instance the focus on self-organisation and widespread political mobilisation by the disability movement has reflected the influence of the women's movement and other liberation movements (Shakespeare, 1994a).

Feminist theory is also useful for disability studies because it has extensively grappled with the questions of how to conduct non-exploitative research. Many years ago, feminists such as Bart (1971), Bernard (1973) and Smith (1974) questioned the appropriateness of traditional data collection methods, and Oakley (1981) argued that feminists must explore the significance of non-hierarchical relationships in their methodologies. Acker, Barry and Esseveld (1983) pre-empted Oliver's (1992) call for "emancipatory" research methods when they demanded that research should not be oppressive, that it should question dominant intellectual traditions, and that it should be self-reflective. The importance of adopting methodologies which are non-hierarchical and non-exploitative has only become a major question in disability studies over the last ten years, particularly since the publication of a special edition of *Disability, Handicap and Society* in 1992. Feminists have a long history of grappling with these questions and it would be foolish for disability studies to ignore this body of literature.

I have also been interested in the way people with brain injuries negotiate their identities—some choose to hide their experience of disability, and pass as nondisabled; others see a great deal of importance in "coming out" as a disabled person; and most use a host of strategies to negotiate their needs within both friendly and hostile environments. In this regard, I have looked to the writings from queer theory in order to better understand the difficulties associated with passing and coming out. There are many other similarities in the experiences of queers and disabled people, including familial isolation, high rates of violence, and the experience of stereotypes and discrimination. As a result, both the queer and the disability movements, and the intellectual disciplines which study them, share many common characteristics. Both queer theory and disability studies share a debt to feminism, and both oppose hegemonic normalcy and deconstruct identity categories. Queer theory, like feminism, is not a unified body of thought, but it is characterized by an approach which consistently problematizes categories of identity (Butler, 1990; Spargo, 1999; Wilson, 2001). Queer Theory is useful because it suggests that binary approaches to identity are fundamentally flawed. One of the strands of queer theory "finds the gaps" between male and female genders—such as the case of intersexed people—and it highlights their significance for the study of gender. "Intersex" is a term used to describe someone who has an anatomy that is neither clearly male nor female (Kessler, 2002). Some of the medical terms used to describe people with such anatomy include Androgen Insensitivity Syndrome, Kilefelter's Syndrome, progestin virilization, mixed gonadal dysgenesis, and true hermaphrodism. Often there is no clear answer to the question "which gender is this child," but the social importance placed on announcing whether the baby is a boy or a girl means that the individual and the family can face complex issues surrounding identity. This literature is useful for disability studies because it provides lessons on how to incorporate the experiences of people who have unorthodox identities—for instance, someone with an impairment who does not identify as disabled. At the moment, they simply "fall through the gaps." People are commonly assumed to be either disabled or non-disabled—those who experience life at the margins are largely ignored. Queer Theory suggests that the "problem" of such identities stems from a binary way of conceptualising the experience. Binary approaches can never capture the nuances and subtleties of lived experience.

Stein and Plummer (1996) argue that queer theory has four main elements: identifying sexual power in different levels of social life, enforced through binary divides and expressed discursively; problematizing sex, gender and identities as fluid categories; preferring anti-assimilationist strategies ahead of civil rights strategies; and being prepared to examine areas which would not generally be regarded as sexual, and providing "queer" readings of non-sexualised or heterosexual texts. Queer theory arose in response to the development of the AIDS epidemic, in particular the individualising nature of medical responses, shifts in sex education from an emphasis on sexual identities to an emphasis on sexual practices, continuing homophobic positioning of AIDS as a gay disease and the coalitional politics involved in responses to AIDS (Jagose, 1996).

Queer theory is also interesting for disability studies because one of its major themes has been whether queers should adopt a political position of assimilation (arguing that they are "just like you" and therefore deserve exactly the same rights as heterosexuals) or whether they should flaunt their differences. The question of assimilation or defiance is also important for disabled people. Queer people have often engaged in flaunting as a form of transgressive politics and flaunting is becoming increasingly popular in the disability movement. Flaunting involves re-claiming words of hatred and turning them into words of pride—e.g. "crip," "faggot," "dyke." Words like "crip" or "gimp" have been reclaimed by some disability activists as a form of cultural defiance. However, Clare (1999) warns that flaunting may be a double-edged sword, because words of hate still retain their original meanings at some level.

Postmodern approaches can also offer disability studies important insights. One ingredient of a postmodern approach which has been identified by Lyotard (1984:xxiv) is "incredulity toward metanarratives." That is, postmodernists are reluctant to develop general theories, and tend to stress that their conclusions are localized and specific. Many postmodernists have contributed significantly to the rethinking of power, self, the body, and identity in contemporary societies. Their work has challenged traditional notions of power, highlighted the importance of language and discourse, emphasized the role of disciplinary mechanisms affecting both macro and micro politics, suggested that the self was decentered and fragmented rather than rational and autonomous, and promoted deconstruction as a way of critically interrogating knowledge and "truth claims." Postmodern approaches recognize that identities have very important personal and social effects, but they emphasize the importance of adopting a critical attitude towards binary and essentialist notions of group identities (Nicholson and Seidman, 1999). Postmodernists also deconstruct traditional notions of oppression and tend to have a more complex and nuanced understanding of the dynamics of power than their modernist counterparts. Drawing upon these insights, I will critically examine the discourse of oppression which underpins a great deal of disability studies literature.

I have also drawn upon the work of Postcolonial theorists. "Postcolonial" is described by Ashcroft, Griffiths and Tiffin (2003:2) as "all the culture affected by the imperial process from the moment of colonization to the present day." Moore-Gilbert (1997:12) adds that "Postcolonial criticism" is

> a more or less distinct set of reading practices, if understood as preoccupied principally with analysis of cultural forms which mediate, challenge or reflect upon the relations of domination and subordination—economic, cultural and political—between (and often within) nations, races or cultures, which characteristically have their roots in the history of modern European colonialism and imperialism and which, equally characteristically, continue to be apparent in the present era of neo-colonialism.

Like disability studies, postcolonialism has demanded inclusion, acknowledgment of difference and analysis of difference, as well as examination of the historical and representational implications of such difference (Bhavnini, 2001:3). I have been able to draw upon concepts from postcolonialism (such as hybridity, ambivalence, exile, and diaspora) and apply them to the experiences of people with a brain injury. For instance, these concepts can be applied to the social exclusion and physical dislocation of brain injury survivors who are homeless, or young survivors who are placed in aged care homes.[1] Likewise, the enfreakment of some disabled people in medical textbooks, biographies and even in freak shows could be interpreted through the lens offered by the post-colonial concept of the "exotic." However, I am not simply basing my arguments on an additive model of identity which supplements previous work on disability with a post-colonial edge. I am actually asking how concepts from both disability studies and postcolonialism would change if we fully integrated both disciplines. As women of color (such as Amos and Parmar, 2001) have agued with regard to race and gender, the intent is not simply to make 'visible' the experiences of a marginalized group: it involves a fundamental rethinking of the analytical categories and essentialisms contained within them.

Postcolonialism is incredibly useful for disability studies, I would suggest, when it discusses the topic of identity politics. In this respect, another Postcolonial theorist, Kwame Anthony Appiah (1999), argues that three common assumptions often underpin conceptions of ethnicity: an assumption that there is a common biological foundation; an appeal to a sense of shared history; and a suggestion that people share a common culture. This insight is useful because it is sometimes suggested that disabled people share common biological, historical or cultural backgrounds, which fundamentally differentiate them from non-disabled people. The following comments from Susan Wendell (1989: 117) reflect these assumptions about disabled people:

> We are dis-abled. We live with particular social and physical struggles that are partly consequences of the conditions of our bodies and partly

> consequences of the structures and expectations of our societies, but they are struggles which only people with bodies like ours experience.

Branfield (1998: 143) goes further and argues that non-disabled people can never fully understand the oppression of disabled people:

> . . . whilst disabled people are not necessarily politicized to our oppression, by virtue of being disabled alone, the disability movement reflects a socio-political reality. For disabled people, this reality is immediate, growing out of our lived experience and producing a direct knowledge for change, for action. 'Non-disabled' people cannot fully know this. For them, their experience, their history, their culture is our oppression.

Postcolonial literature suggests such a binary and essentialist approach to identity is conceptually flawed, inconsistent and has undesirable moral and political consequences. For instance, postcolonial feminists have challenged the essentialist assumption of unity and solidarity among "women qua women" (Amos and Parmar, 2001). Bryan's (2001) study of black support groups also suggests the need for a reconceptualization of "black identity" so that the differences between the ways individuals position themselves and hegemonic constructions of their identity are explored. She stresses that the struggle for hegemony is played out not only at national or international levels, but also between individuals and groups. "Black identity" is far more complex than a simple black/white dichotomy might suggest. In this book, I suggest that in the same way that a black/white divide is theoretically inadequate for conceptualising ethnicity, and a male/female binary is inadequate with respect to sex and gender, the disabled/non-disabled divide is also deeply problematic and conceptually limited. People often position themselves somewhere in-between or outside these binary categories, and this positioning is fluid and contextually dependent.

Postcolonial literature is also useful to disability studies because it emphasises that identities are always enmeshed with gender, ethnicity, class, religion, and other social factors. Appiah (1999: 113) stresses that appeals to "African solidarity" may have political mileage but are always problematic in some sense:

> To accept that Africa can be in these ways a usable identity is not to forget that all of us belong to multifarious communities with their local customs; it is not to dream of a single African state and to forget the complexly different trajectories of the continents so many languages and

> cultures. "African solidarity" can surely be a vital and enabling rallying cry; but in this world of genders, ethnicities, and classes, of families, religions, and nations, it is as well to remember that there are times when Africa is not the banner we need.

In the same vein, disability studies must recognize that although a sense of disability identity may be important politically, there will be many occasions when people choose to position themselves according to other social factors. That is, disability studies needs to recognise that there are times when "disability" is not the banner we need.

RESEARCH QUESTIONS

The study upon which this book is based was guided by one primary research question, and three secondary research questions. In the research, the term "Acquired Brain Injury" (ABI) was used. ABI is the most popular term in Australia for this experience. It is a broad term referring to any type of injury to the brain which occurs after birth, including as a result of strokes, motor vehicle accidents, falls, alcohol-induced brain injury, neurological diseases and many other conditions (Commonwealth Department of Human Services and Health, 1994). Traumatic Brain Injury (TBI) is a subset of Acquired Brain Injury which refers to those brain injuries which occur suddenly when the brain is hit, penetrated, twisted or violently shaken (Winslade, 1998). Traumatic brain injuries produce sudden and immediate impacts upon the individual concerned.

KEY RESEARCH QUESTION

What does the experience of Acquired Brain Injury tell us about impairment, disability, embodiment and identity?

SECONDARY RESEARCH QUESTIONS

- Has the literature on ABI tended to rely on a medical model of disability? How different would our understanding of ABI be if we relied on a social model?
- How can we best understand disability, impairment, identity and embodiment—through a medical or a social model, or something else? How could these models be improved?

- Can disability studies learn something from other disciplines such as feminism, queer theory, postcolonial and postmodern literature? Can these disciplines learn something from disability studies?

I shall now provide a brief “working definition” of some of these key terms. Following the work of Merleu-Ponty (1962), I would define “*embodiment*” as the process through which the body operates in the world. According to Williams and Bendelow (1998), embodiment lies ambiguously across the nature/culture divide: it is lived and sentient, as well as expressive and mindful. Following Frank (1991), they position embodiment at the intersection of the corporeal, the discursive and the institutional. Embodiment is at once a personal and a social process, involving the way we experience and interpret our bodies. In arguing for an increased emphasis on embodiment, I want to distinguish my own position from that of authors who argue that there is no material body outside discourse. For instance, I would disagree with Tremain (2000: 296) who argues:

> “ . . . the body” has no pre-given materiality, structure or meaning prior to its articulation in discourse.

Instead, I would side with feminist authors such as Grosz (1994: 23–24) who argue for a “corporeal feminism” and problematize the body as being situated at the intersection of the biological and the discursive:

> In the face of social constructionism, the body’s tangibility, its matter, its (quasi) nature may be invoked; but, in opposition to essentialism, biologism, and naturalism, it is the body as cultural product that must be stressed.

“*Impairment*” is a narrower category than embodiment. Within disability studies, a discussion of impairment usually involves situating bodily difference within a biomedical paradigm which labels and measures deviation from a “norm” (Paterson and Hughes, 2000: 42). However, more recently disability studies has begun to recognize that the experience of impairment, like embodiment, is both a social and a personal one (Hughes and Paterson, 1997).

“*Disability*” refers to the social oppression which people with impaired minds or bodies experience. Disability is a fluid category. Not all impaired people are disabled in every context (Oliver and Barnes, 1998).

"Identity" is a subject position. Hall (1996) stresses that identities are fluid categories which are constructed through difference. Identities are representations that always involve exclusions. Every identity has an "Other" and a "margin" which tests its validity. Identities are often shifting, fragmented and fractured.

WHY STUDY BRAIN INJURY?

One of the reasons why I am studying brain injury is that my personal experience has helped me to understand its relevance to many debates about identity politics within feminism, postcolonialism, postmodernism and disability studies in recent years. As well, it is an intrinsically interesting topic: it is important as a public health issue; it has serious and often life-threatening consequences; welfare and health sectors have often responded poorly to the needs of people with brain injuries; and it has been rather neglected within disability studies.

Identity Issues and Brain Injury

If someone survives a brain injury, they inevitably face the challenges of disclosure: who to tell, what to say, how to frame the discussion, and so on. How people with a brain injury meet this challenge tells us a lot about the way we manage our identities, and how those identities sometimes seem to manage us. Over the last 20 years there has been a veritable explosion of writing on the field of identity—but the experience of brain injury has been largely ignored in this literature. This is interesting, because we tend to assume that negotiating an identity involves a fairly high level of cognitive ability—an assumption which may or may not be true.

Brain Injury as a Public Health Issue

The research for this book was conducted in Australia, where over 339,000 people are disabled because of an Acquired Brain Injury (ABI). It was also conducted in Queensland, the state with the highest rate of ABI in the country (Fortune and Wen, 1999). Although some of the dynamics are clearly local issues, such as those dealing with specific welfare agencies, or problems associated with Australia's health and insurance system, there are many people with a brain injury all over the world who are dealing with similar problems—trying to understand the changes in their minds and bodies, getting welfare, finding work, dealing with social isolation, and so on. Brain injury is a major public health issue in every country—the US Center for Disease Control (2003) estimates that approximately one and a half million Americans experience a traumatic brain injury every year, and the British organization Headway suggests that every year, approximately a million English people attend hospital as a result of head injuries.

Severity of the Impairments Resulting from Brain Injury

ABI is a severe impairment with damaging personal, social, economic and political effects. Indeed, ABI often has lifelong effects on people's daily living activities, employment and social activities, and on their cognitive, social, physical, and psychological capabilities. Winslade (1998: 43–44) states that half of the people with serious brain injuries are unable to bathe, feed or dress themselves within three months. For those in a coma, the statistics are worse: 40% die without returning to consciousness, 20% are either in a persistent vegetative state or are severely disabled and 40% recover but may still have some permanent disability. Survival from certain types of head injury is a relatively recent phenomenon; it is only since the 1980s that survival became possible following moderate or severe ABI. Since then, individuals who sustained a moderate or severe ABI have tended to survive the acute onset. Increased survival rates have partly been the result of advances in road safety, medical research and medical technology (Winslade, 1998).

ABI is Poorly-Resourced

One of the reasons why I was inspired to write this book is that in Australia, brain injury is, and has been, one of the most poorly resourced of all impairments. Accordingly, significant levels of unmet need exist for most brain injury survivors. Such unmet needs have been recognized in many reviews of service provision, including the *Discussion Paper on the Needs of People with Acquired Brain Injury* published by Disability Services Queensland in conjunction with the Acquired Brain Injury Outreach Service and the Brain Injury Association of Queensland (2000), the *Study into the Accommodation Needs of Young People Requiring Nursing Home Level of Care* by Melbourne Citymission (1999), *Making Rights Count: Services for People with a Disability* published by the Commonwealth Department of Health and Family Services (1996), and the *Review into Service Provision in Queensland* by Elizabeth Kendall (1991). An analysis of these reports indicates that unmet needs include:

- problems with diagnosis and inadequate staff training in acute care;
- barriers to rehabilitation, including lack of services and exclusionary eligibility criteria;

- insufficient community living options and shortages of appropriate respite care;
- financial problems, particularly for people without compensable injuries;
- the need for vocational and educational assistance;
- the need for public education around brain injury;
- lack of support for family members and carers;
- lack of services and transport for people in country areas; and
- lack of culturally appropriate services for people from Aboriginal and Non-English Speaking Backgrounds.

ABI is Marginalized within the Social Model

Studying ABI has not yet been a major priority for writers who support the social model of disability. Chappell (1998: 212) argues that very little research has been done within the social model on non-physical and non-sensory impairments and that "some of the arguments emanating from within the social model are assumed to refer to all disabled people, when in reality they do not." Some authors, such as Longmore (2003), Olkin (1999), Garland-Thomson (1997a) and Wendell (1996) are explicit: they are talking about "physical disabilities" (sic)—cognitive impairments like brain injury are simply ignored. Chappell was writing about the failure of such theorists to consider the position of people with "learning difficulties." However, since the publication of Chappell's work, there has been a considerable growth in this body of literature, with contributions from Atkinson and Walmsley (1999), Dowse (2001), Goodley (2001, 2000), Knox, Mok and Parmenter (2000), and Young and Quibell (2000). Nevertheless, the area of brain injury is still neglected within the social model. Chappell (1998: 212) suggests that as long as a significant number of impairments are ignored within the social model:

> . . . the danger is then that the analyses which emerge from the sociology of disability are theoretically flawed and their explanatory power is weakened.

The failure of social model theorists to incorporate the experiences of brain injury survivors in their writing may be particularly significant, given that the experience of brain injury has some unique elements. For instance, the experience of a coma, the lack of awareness which accompanies some brain injuries, the experience of rejection by services which cater for other disabled people, and the complex social, ethical and biological issues associated with the "vegetative state" involve important issues around citizenship, recognition and embodiment which are quite unique to this impairment. By examining the extent to which our theorizing of disability needs to be improved to incorporate the experiences of people with an ABI, this research aims to fill an important gap in the existing literature.

METHODOLOGY

This research project adopted a qualitative and participatory approach. It involved data collection through in-depth interviews, conducted both individually and in groups, a process of keeping a reflective journal and field notes, and participant observation. Another important aspect of the study involved being self-critical; reflecting on my personal experience of brain injury and examining the extent to which this has influenced the research process. As well, the study confronts the ethical question of how to involve other brain injury survivors in the research process without exploiting them. This is a major methodological question given that many disabled people find traditional research methods oppressive (Barnes and Mercer, 1997; Oliver 1997). In order to address this ethical issue, I used a combination of theoretical and empirical methods including a disability studies framework, "insider" research, and "emancipatory" research methods. I recognise that the term "emancipatory" disability research implies to some extent that all disabled people are heading in the same direction towards one goal of liberation. Later in the book, as I discuss the complexity and heterogeneity of the movement, and the Foucauldian conception of power which problematizes concepts of oppression and emancipation, I explore some of the reasons why I am somewhat uncomfortable with this phrase. Nevertheless, the phrase "emancipatory" research is quite dominant in disability literature and is a useful signpost for the direction of the research.

A "Disability Studies" Framework

I decided very early in my research to adopt a "disability studies" focus rather than a traditional (positivist) approach. Although disability studies is not a unified body of thought, I have chosen to link my work with this field because it has sought to establish alternatives to the traditional approaches which are widely seen as oppressive to disabled people. Oliver (1992) argues that traditional research methodologies have been a "rip off" which have done almost nothing to address the social oppression which disabled people experience on a daily basis. He suggests that if it is to help improve the lives of disabled people, research needs to move in a new direction, examining what he terms "institutionalized disablism" in all its forms.

Morris (1992: 157) likewise suggests that research into disability issues is usually perceived by disabled people as part of the problem, rather than part of any solution. Linton (1998a) has also identified the flaws of the traditional positivist approach towards disability. She argues that the traditional approach is characterized by the absence of disabled voices. The dominant emphasis is on individual rehabilitation; interventions are not intended to change the context or environment. Environmental changes are demanded by the social model and a "disability studies" approach.

While the social model is nowhere near as important in Australia as it is in Britain, either in policy frameworks or in the consciousness of disabled people, it is still influential among sections of the disability movement. For instance, a recent Australian publication states that it "openly embraces a social perspective on disability" (Clear, 2000: xiv). However, a number of the peak bodies in the disability movement are still organized along impairment lines and operate according to the "charity" model.[2]

"Insider" Research

My research could be labeled "insider" research in the sense that I am one of the people being studied as well as the researcher. Again, I need to register my unease (at the outset) regarding any essentialist identity category which suggests only "insiders" have legitimacy. Such identity categories are usually used to exclude, rather than include. However, I must recognize that I am an active member of various brain injury and disability groups, and participants in the study have been recruited from one of those groups. I have a very close relationship with these people, based on our shared experiences, our long-standing friendships and our open, honest, trusting and supportive relationships. This is a strength rather than a weakness of the research—it is precisely the sort of committed research which disability scholars have demanded—for instance, Moore, Beazley and Maelzer (1998), Oliver (1992), and Stone and Priestley (1996). By involving other brain-injury survivors with whom I have well-established and frank relationships, I have jettisoned the traditional "mystique" of a researcher. I have non-hierarchical relationships with the research participants, based on mutual respect. The level of honesty and trust amongst us meant that each participant felt more at ease identifying areas which were important to them. My accountability and accessibility has also provided a richness of experience that would have been impossible using any other methodology. However, I am acutely aware that the issue of setting appropriate boundaries can be quite a challenge in "insider" research. I have therefore paid special attention to the issue of defining what material "is" and "is not" part of the research process.

Central to “insider” research is the issue of engagement (Smyth and Holihan, 1999). Unlike other researchers, “insiders” may be expected to have ongoing relationships with members of a group, and may be in formal or informal positions of authority. Relationships within the group and personal alliances seem more important in “insider” research. I am therefore fortunate that I seem to get on fairly well with everyone in the group. Our group, the Brain Injury Action Group, does not have a formal organizational structure, but certainly there are informal power relationships. On reflection, I have probably received some informal authority within the group because I speak well, I know a lot about brain injury and I am skilled at identifying systemic issues (such as the need for better supports in the transition from hospital to the community). Some of the others talk mainly about their own personal experiences and find it hard to generalize beyond those experiences. Others are shy and feel uncomfortable speaking, even in informal settings. Speaking in public would be impossible for some members of the group at this point in time. This has meant that I have been asked to speak at disability meetings whereas others in the group may not have been given that opportunity. In order to discourage being a de-facto “leader” within the group, I have tried to spend time listening to the others and have encouraged and supported them when opportunities to talk in public have arisen. I have also told some of the shy people that when they do speak in our group, everyone really appreciates their comments and participation. My approach is meant to be empowering and everyone has been encouraged to talk about our experiences as widely as possible.

There are significant dangers in conducting “insider” research, and I have been aware of these throughout the research process. For instance, two major methodological concerns which “insiders” often have to deal with are questions of bias and credibility of research results. I have tried to address these issues by paying particular attention to the reliability and validity of my conclusions. One way I have done this is by using multiple data collection methods, including interviews, personal narratives, group meetings, field notes, a journal, and participant observation. A process of member checks has also been developed to ensure that I am not imposing my personal framework upon other research participants. Also, I have searched for discrepant data as another way of testing the validity of my research.

The tradition of “insider” research is well-established in anthropological, feminist and disability research (Barnes, 1990; Bolak, 1995; Morris, 1991; Zinn, 1979). Within these disciplines, it is often suggested that “insider” research can play an important role in personal liberation, giving people a new way of seeing their lives. However, there seems to be a tendency within some of this literature to adopt a less rigorous approach to the process of data collection and interpretation. Rose (1978) suggests that "insiders" are fundamentally different from "outsiders" because "insiders" have privileged access to certain knowledge, feelings and experiences. Rose suggests that this privileged access to information means that "insiders" do not need to focus on their professional tools or methodology. I disagree strongly with Rose's argument. I am uneasy about essentialist identity categories which imply that "insiders" and "outsiders" are fundamentally different, and that "insiders" innately "know" the answers to the problems they study. Like other researchers, "insiders" need to develop research methodologies which are rigorous. Also, I feel that positioning "outsiders" as politically irrelevant and necessarily limited in their understanding is a very dangerous strategy for disabled people, limiting the opportunities for coalitions with like-minded people committed to social justice.

Being positioned as an "insider" is not always a good thing—it is an identity category which requires negotiation, the establishment of clear boundaries and a rigorous approach to the data. Researchers who identify themselves as "insiders" still need to be rigorous in their methodology—they need to consider matters such as the reliability and validity of their findings, their influence on the data which is collected, and they need to be vigorous in pursuing alternate explanations for the results of their investigations. Vernon (1997) notes that her research on the experiences of black disabled women is as much about her experiences as it is about other people's. While I think that her acknowledgement was an attempt to recognize her own influence over the research process, I think it is important to be even more reflective than this. Of course, as Farnsworth (1996) and also Vernon (1997) recognize, there is an absolute need for acknowledgment and inclusion of the researcher's personal experiences in any "insider" research project. But it is equally important to acknowledge the potential for projection and researcher bias. Being disabled is not a sufficient condition for credible research results. Like other researchers, disabled people need to be rigorous and defend the methodological choices they make, such as decisions over the recruitment and selection of research participants, the level of involvement of participants, the degree to which data analysis is a shared or collective effort, and they need to discuss the safeguards which they set in place to ensure that participants are dealt with in an ethical manner.

It needs to be acknowledged that although I have been influenced by the group discussions which we have held, the data analysis in this book is my own. There is a need for academics to maintain their integrity at the same time as they surrender control of various processes to research participants. Priestley (1997: 92) calls this a tension between "our expertise *as* *researchers*" and "disabled people's expertise *as knowers*." "Insider" research often poses unique challenges in this regard, as the researcher is both a participant and an analyst. Rigorous methodology is therefore essential in "insider" research.

"Emancipatory" Disability Research

The research could also be labeled "emancipatory" research, in the sense that I have worked in a collaborative and collective way with the research participants. They had extensive input into the design of the study and the direction the research has taken. They have been active participants throughout the research process. We have developed an agreement that all of us are trying to break down physical and attitudinal barriers that have made our lives more difficult. We have identified a number of important issues to people with a brain injury—including information, support, advocacy, and rehabilitation. We have also identified areas that can assist families and friends to deal with this experience, as well as identifying areas where medical and welfare systems could be more responsive to our needs. One component of this research has been to hold meetings with disability organizations and with government agencies to try to influence the direction of their policies with regard to brain injury.

Moore, Beazley and Maelzer (1998: 14) argue that the following principles underpin "emancipatory" disability research:

> For us, it should not be embedded in, or regulated by, medical model ideologies; it should not attempt to be neutral or to disregard the impact of oppression on disabled people's lives; it should not reproduce the familiar, and so leave disabling personal, political or practical barriers unchallenged; it should not exclude disabled people from its process or productions; it should not be controlled entirely by non-disabled people and it should not be reluctant to venture in to unmapped theoretical and methodological territory.

I agree with Moore, Beazley and Maelzer that disability research needs to be grounded in values which respect and uphold the rights of disabled people. However, once again I am uneasy about adopting the rhetoric of "emancipation," or committing myself totally to an "emancipatory" framework. The language has a certain vanguardist tone which makes me feel uneasy—like the Leninists before them, this path towards "emancipation" has been designed by intellectuals, albeit disabled ones. I prefer to highlight the values to which I have committed myself, particularly being attentive, responsive and responsible to the participants. One of the reasons for my unease with the “emancipatory” model is that it is sometimes asserted that in order to be “emancipatory,” research must be thoroughly committed to the social model of disability. Stone and Priestley (1996: 706) are quite explicit and even prescriptive on this point. They argue that the first principle of “emancipatory” disability studies is “the use of the social model of disability as the epistemological basis of the research.” If their argument is correct, then this study cannot be labeled “emancipatory.” However, I would argue that the suggestion that only one theoretical framework can be considered “emancipatory” is a political position which is arrogant in the extreme.

OUTLINE OF THE BOOK

In Chapter Two, I describe the impairment (Acquired Brain Injury) in more detail. I define brain injury and consider some of the characteristics of different types of brain injuries (such as open or closed injuries, severe and mild injuries and injuries to different parts of the brain). Some factors relevant to the epidemiology of brain injury are also discussed and the effects of a brain injury are considered. Many of the social dynamics which affect brain injury are also discussed, including brain injuries which result from domestic violence. The emphasis of postcolonialism on relations of domination between (and within) nations, races and cultures may also be useful in recognizing that brain injury is not evenly distributed across the population, but is actually skewed according to socioeconomic position, race and ethnicity. This insight suggests a need to examine whether the needs of different ethnic groups are being met in the provision of services for people with brain injuries. Finally, the chapter demonstrates that the medical model of disability underpins much of the literature on brain injury. Some of the strengths and limitations of the medical model are also discussed.

Chapter Three examines the literature within disability studies which focuses on the social experiences of discrimination, marginalization and exclusion that many people with impairments experience. Informed by the social model of disability, this literature highlights social reactions to impairments, rather than those impairments themselves. The chapter begins by defining disability and identifying disabling barriers. It then discusses the effects of disability and considers various ways of responding to disability. The theoretical underpinnings of the social model of disability are also examined and some of the weaknesses of the social model are identified. The chapter acknowledges the importance of the social model in terms of understanding the experience of disability, but it also identifies areas which have been under-theorized in the social model, such as the experience of embodiment, identity, and the operation of power.

Chapter Four involves a discussion of the methodology used in this book. The analytical and methodological framework for this research involves a combination of approaches, particularly disability studies, "insider" research, and some elements of an "emancipatory" research approach. The methods used for data collection and analysis are discussed at length in this chapter. Ethical issues raised by the study, and unique methods adopted for working with ABI survivors, are also outlined. Finally, the methodological limitations of the research (especially in terms of reliability and validity) are considered.

Chapter Five outlines the data obtained from interviews and other sources which document the nature of the impairments experienced by participants in this study. Generally a discussion of issues associated with impairment tends to be consistent with the medical model in the sense that the focus is on the nature, cause and severity of the impairment. In a discussion of brain injury, such features include a discussion of the length of time individuals were unconscious, and the personal challenges which they experienced after their injuries (such as memory and organizational problems, behavioral and emotional difficulties, and difficulties with the tasks of everyday living). Chapter Six outlines another dimension of the stories of research participants by examining the barriers which we have experienced since our injuries. This chapter virtually provides a "social model of brain injury." It explains many of the social barriers which participants have identified as being important in their lives. Such barriers include inadequate rehabilitation, being "written off," experiencing social isolation, and having inadequate support and inappropriate accommodation options.

Chapter Seven presents a range of data which does not neatly fit into either the social or the medical models of disability, but is more consistent with the insights gained from the discussion of feminism, queer theory, postmodernism, and postcolonialism. Such data includes a discussion of the complexity of disability as an embodied experience and the complexities of issues associated with identity. Feminist insights on embodiment may not have been integrated enough within disability studies, even though different forms of embodiment often correspond to different kinds of experience (Spelman 2001). Likewise, the complexities of dealing with a marginalized identity (such as deciding how and when to disclose the identity, and whether to transgress or assimilate) are highlighted in queer theory but may have received less attention in the literature on brain injury. Chapter Seven also highlights the challenge Michel Foucault's reconceptualization of the concept of power presents for understanding individual and collective agency in resisting disabling barriers. Utilizing an interdisciplinary approach which acknowledges the complexity of disability as an embodied and lived experience, this chapter represents the major theoretical advance of the book. It points to a number of ways in which disability theory can move beyond its structuralist foundations in order to incorporate a greater focus on identity, embodiment, human agency and culture.

Chapter Eight, the Conclusion, summarises the results obtained in this study and discusses their importance. New practical, methodological and theoretical directions for disability studies are outlined. The data collected in the study highlights some inadequacies in both the medical and the social models and suggests there is a need for theorising which recognises the diversity of experience within the disability movement. It is suggested that one option for recognising such diversity is a fuller engagement with critical theories such as postmodernism, queer theory, feminism and postcolonialism.

CONCLUSION

This chapter has laid the foundations for the book. It has identified the research problem and outlined the key research question and subsidiary questions. The research was justified both in terms of the significance of ABI and the important gaps in the literature which the book seeks to address. A cross-disciplinary approach to the subject matter, drawing from feminism, queer theory, Postcolonial and Postmodern literature, as well as the medical and social models of disability, was outlined. The research methodology was also described and justified in terms of current debates about doing disability research and the dilemmas of “insider” research. The book can now build upon these foundations and proceed with a detailed investigation of the subject. The next chapter will outline the nature and effects of a brain injury, and will suggest that the medical model of disability has been the dominant theoretical framework in which brain injury has been interpreted. Flaws in this theoretical framework will also be identified, and areas requiring further investigation will be highlighted.

Chapter Two

Understanding the Impairment (ABI)

INTRODUCTION

This chapter outlines the nature and effects of a brain injury. The medical model of disability dominates the literature on brain injury and is inextricably linked to certain medicalized responses to brain injury within the health system. This chapter discusses common elements of the experience of ABI, but also highlights assumptions about this experience that stem from the particular approach of the medical model. It defines brain injury and considers some of the variables affecting brain injury (such as the severity and the site of the injury). It also outlines some factors relevant to the epidemiology of brain injury and discusses the effects of a brain injury which have been identified in the literature. While there has been substantial criticism of the medical model and its exclusive focus on impairment (rather than disability) for more than a decade, there have been recent calls from disability activists to take the issue of impairment seriously. Shakespeare (1999: 684) for example recently stressed “the need for both disabled people and clinicians to understand the issue of impairment more effectively.” Impairment is important as a lived, sentient, corporeal experience which requires certain regimes of bodily control and often elicits significant physical and cultural responses.

WHAT IS BRAIN INJURY?

Definitions of Acquired Brain Injury are not uniform within Government, rehabilitation or medical literature. Yet a working definition of ABI is absolutely essential in order for us to be clear about the nature of the impairment. The *National Policy on Services for People with an ABI*

(Commonwealth Department of Human Services and Health, 1994: 29) defines an ABI in the following way:

> Acquired Brain Injury is injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.

This definition makes it clear that neurological conditions such as Multiple Sclerosis or Huntington's Disease are included as forms of acquired brain injury. ABI is therefore a complex and individual condition which can be the result of accidents, strokes, alcohol or drug abuse, tumors, poisoning, infection and disease, near drowning, hemorrhage, AIDS, Parkinson's disease, Multiple Sclerosis, Alzheimer's disease and other forms of dementia. ABI is a category used more commonly in government reports than in medical diagnoses. Medical diagnoses tend to be far more specific, such as a diagnosis of Multiple Sclerosis, Traumatic Brain Injury or Stroke. In effect, ABI is a political term rather than a medical one. It is a political term used in the distribution of scarce health resources, but there are often significant differences in the experiences and impairments of people broadly categorized as having an ABI. There are many reasons why people with one form of ABI may choose to differentiate themselves from other people with different forms of brain injury. For instance, a 15 year old boy with an alcohol-induced brain injury may have little in common with a 65 year old man who has had a stroke or a 30 year old woman who has received her brain injury as the result of domestic violence.

VARIABLES AFFECTING A BRAIN INJURY

The medical model places huge significance on the aetiology of a brain injury, that is, the specific causes of the injury. In this regard, it distinguishes between:

- Open and closed head injuries;
- Traumatic and non-traumatic brain injuries;
- Injuries to different sections of a brain;
- Mild, moderate and severe brain injuries; and

- Pre-morbid characteristics of the individual which may effect the brain injury.

Open and Closed Head Injuries

A brain injury is usually a series of injuries: a primary injury, such as that caused by a blow to the head, and secondary injuries which result from swelling, bleeding and other chemical responses to the first injury. Often an injury in one part of the brain (such as the frontal lobe) leads to another injury opposite the point of impact. This is known as the coup-contrecoup effect (Kenig, 1986). The presence of haematoma may also compound and complicate the effects of a brain injury. In diagnosing the cause of the (first) injury, the medical model distinguishes between closed head injuries and penetrating injuries. Closed head injuries do not break the skin; the injuries are locked inside the brain. Open head injuries, or penetrating injuries, do pierce the skin. Secondary injuries are often caused by a lack of oxygen, swelling, bruising and bleeding (Gronwall, Wrightson and Waddell, 1998).

Traumatic and Non-Traumatic Injuries

The nature of the damage is greatly affected by the way in which it is acquired. Traumatic Brain Injury (TBI) is characterized by different aetiology and epidemiology than non-traumatic brain injury. The population with traumatic brain injuries tends to be younger than those with non-traumatic brain injuries. Kushner (1998: 1617) defines a TBI in the following manner:

> Traumatic brain injury may occur with or without evidence of external trauma following violent contact forces or rapid acceleration/deceleration movements of the head. The usual causes include assaults, crashes, and accidents involving motor vehicles, bicycles, pedestrians, construction, and sports. Definitive signs must be present at the time of head trauma for a traumatic brain injury to be diagnosed. These signs include confusion, loss of consciousness, amnesia, and focal neurological deficits. Traumatic brain injury is classified at the time of injury by certain measures, including duration of loss of consciousness, duration of posttraumatic amnesia, and the Glasgow Coma Scale (GCS) score.

Adams (1996: 75) suggests that in Australia, 75% of people seen at an ABI clinic would have experienced a TBI. This statistic does not necessarily mean that traumatic brain injuries constitute the vast majority of brain injuries. For instance, according to the Alcohol Related Brain Injury

Assessment Support group, there are large numbers of people with alcohol-induced brain injuries and other forms of ABI who never consider attending such clinics (ARBIAS, 2001: 2).

Injuries to Different Parts of the Brain

Different parts of the brain serve different functions, so injuries to specific areas are commonly associated with particular outcomes. In this regard, it is useful to understand the functions of the cerebral cortex, the limbic system and the brain stem. The cerebral cortex is composed of four lobes—the frontal, parietal, occipital and temporal lobes. The frontal lobe, which takes up 29% of the total cortical space, is the largest and most commonly injured part of the brain, followed by the temporal lobe (Uomoto, 2000).

Damage to the frontal lobe can be expected to lead to problems with executive functions (planning, initiating and complex reasoning) as well as regulating the emotions (Uomoto, 2000: 16). The frontal lobe is the home of the personality (Chow, 2000) so damage to the frontal lobe is also usually associated with problems with judgment, increased impulsivity, irritability and aggression. The parietal lobe is the primary sensory area of the brain, so damage to the parietal lobe may result in loss of body sensations associated with touch, pressure, and hot or cold (Higgenbottom, 1998: 15). Also, mathematical ability can be reduced when the parietal lobe is injured. The occipital lobe is responsible for visual perception. A damaged occipital lobe is likely to be associated with reduced capacity for recognizing and interpreting visual input (Uotomo, 2000: 18). The temporal lobe is thought to play a major role in memory, control of behavior and hearing. Damage to the left temporal lobe can mean that a person cannot understand speech (Higgenbottom, 1998: 15).

The limbic system consists of the amygdala, hippocampus, basal ganglia, septum, fornix, cingulated gyrus, and some of the anterior thalamus and the hypothalamus. Aggressive and fear reactions, which are mediated in the limbic system, can be altered as a result of injury to the brain. The ability to store and manipulate information can also be damaged when the limbic system is damaged (Uotomo, 2000: 18).

The brain stem contains the reticular formations, pons, medulla oblongata, substantia nigra and the cerebellum. The cerebellum coordinates voluntary movements by influencing muscle activity and controls equilibrium because of its connections to the spinal cord and the vestibular system (Bizzi, Tresch, Saltiel, and d'Avella, 2000). So a person with an injured cerebellum is likely to have difficulties with balance. Damage to the brain stem commonly affects the sleep cycle and alertness (Uotomo, 2000: 20).

Mild, Moderate and Severe Injuries

As well as identifying the part of the brain which is injured, doctors also differentiate people according to the severity of their injuries. A person with an injured brain may be given the diagnosis of mild head injury, moderate head injury, or severe head injury. The diagnostic technique used to measure a person's responsiveness to commands, which forms the basis of the labels "mild, moderate and severe brain injury" is the Glasgow Coma Scale (GCS), which is outlined in Table 2.1 (Source: Powell, 1996: 23).

The Glasgow Coma Score is obtained by adding the individual score for each of the three components: verbal response, eye opening and motor response. Many doctors regard a GCS between 13 and 15 as a sign of a mild injury, between 9 and 12 as a moderate injury, and below 9 as a severe injury. An improved GCS is widely regarded as a sign of a person's improvement over time.

However, the GCS is not without its critics. Kraus (1987: 3) has summarized some of these criticisms:

> Although the GCS is a widely accepted and practical procedure to evaluate coma, it has a number of limitations. For example, eye opening may be impossible with facial swelling, and verbal response may be precluded by an endotracheal tube. The use of drugs to reduce intracranial pressure, as well as alcohol, will affect the patient's response. The reliability of the GCS has been questioned in infants and young children, those who do not understand English, or those having chronic conditions that affect motor, verbal or eye response. Because the GCS is used in many studies that report findings by severity, the possibility of misclassification of severity, for the reasons discussed above, must be of concern.

The GCS is seen as the most useful early indicator of residual neurobehavioural functioning, but it is unable to reliably predict long term outcomes (Levin, 1987: 445). Also, the GCS has limited validity for people whose scores fall between 13 and 15—such scores do not clearly translate into neuropsychiatric sequelae (McCullagh, Oucherlony, Protzner, Blair and Feinstein, 2001). The length of Post-Traumatic Amnesia (PTA) is therefore also used as an indicator of the severity of a brain injury. Examining PTA can be particularly important in cases where people have a long period of confusion after a relatively short period of unconsciousness (Levin 1987: 446).

Table 2.1 Glasgow Coma Score

Glasgow Coma Scale	
Eye Opening	
Spontaneous	4
To Speech	3
To Pain	2
Nil	1
Best Motor Response	
Obeys	6
Localizes	5
Withdraws	4
Abnormal Flexion	3
Extensor Response	2
Nil	1
Verbal Response	
Orientated	5
Confused conversation	4
Inappropriate words	3
Incomprehensible sounds	2
Nil	1
Total Glasgow Coma Score	

The Glasgow Outcome Scale, developed by Jennett and Bond (1975), measures outcomes from brain injury and is outlined in Table 2.2. It identifies five possible outcomes: good recovery, moderate disability, severe disability, vegetative and death. As this Table demonstrates, for people who live but do not show neurological activity over time, the label “vegetative state” is applied.

Table 2.2 Glasgow Outcome Scale

Good Recovery	Resumption of "normal life," may have minor neurological or psychological deficits
Moderate Disability	Disabled, but independent in activities of daily living and in the community
Severe Disability	Dependent on others for daily support
Vegetative	Unresponsive and speechless
Death	

(Adapted from: Jennett and Bond, 1975: 481)

Jennett (1996: 6) defines the following characteristics of people in the "vegetative state":

> The essence of this state is wakefulness without awareness. There are long periods of wakefulness, the relationship of which to normal diurnal rhythms may be difficult to assess because such patients (at least initially) are in continuously lit intensive care units, being turned regularly by nursing staff. The eyes are roving, sometimes dysconjugate, and may briefly seem to follow a moving object; sudden light, sound or movement may evoke an orienting response toward the stimulus. The limbs are usually spastic, often symmetrically so, and they show the withdrawal responses to pain, which may cause facial grimacing or perhaps groaning. Reflex flexion and extension of one or another limb may occur in the response to imposed neck turning. Grasping and groping reflexes may occur in the hands and may be misinterpreted by unskilled and wishful-thinking observers as voluntary or responsive activity.

It is important to note that some people do recover, despite being labeled "vegetative." Andrews (1993) examined a small number of such cases and found that these people were typically quite severely impaired. Only 4 of the 11 in Andrews' study were able to speak, while 6 could communicate yes or no answers through nonverbal means. The outcomes of people who are "post-vegetative" (sic) is currently under-researched.

Premorbid Characteristics Affecting Brain Injury

There are a number of pre-existing factors which can influence the outcome of a brain injury. Pre-injury behavior and psychosocial factors have a significant impact on outcomes from brain injury. For instance, a history of substance abuse can have major effects on both the nature of a brain injury and the potential for recovery (Kolakowsky-Hayner and Kreutzer, 2001). Personality type can also be a significant factor in recovery from a brain injury (Priganto, 1987). It is suggested in some of the literature that certain premorbid characteristics predispose some people to brain injury (Wood 1989: 87). For instance, a tendency to drink drive is a high-risk factor in predisposing someone to a brain injury. Connections between alcohol abuse and brain injury are also well established. In one study of people with mild head injuries, almost 50% of people with mild head injuries were experiencing alcohol intoxication (Biberthaler, Mussack, Wiedemann, Kanz, Gilg, Gippner-Steppert, and Jochum, 2000).

EPIDEMIOLOGY OF BRAIN INJURY

Fortune and Wen (1999) stress that different forms of ABI have different causes and typically affect different age groups and genders in different ways. Males had a significantly higher rate of Traumatic Brain Injury (TBI) than females. Fortune and Wen reported that nearly 70% of people with a TBI were male. Also, younger people tended to have more Traumatic Brain Injuries. The age groups with the highest rates of TBI are those between 15–19 and 0–4 years of age. The age group with the lowest rates of TBI is the 45–64 age range. Typically, people with brain injuries as a result of strokes were older. Fortune and Wen (1999: 77) state that in the case of strokes, the rates for people under 65 were relatively low, but were almost 30 times greater for people over 65. The case of alcohol-related brain injury is different again. However, Fortune and Wen were not in a position to provide comprehensive data on alcohol-related brain injury. This limitation was due to a combination of the lack of research in the area, under-diagnosis by health professionals and the reluctance on the part of individuals to admit to such a stigmatizing condition. Fortune and Wen also examine other causes of ABI, such as Multiple Sclerosis, but stress that these conditions are often labeled “neurological disabilities” rather than brain injuries. Unlike traumatic brain injuries, multiple sclerosis affects far more women than men. Women are two to three times more likely than men to have Multiple Sclerosis (Fortune and Wen, 1999: 56). Similarly, dementia (for instance, Alzheimer’s disease) and Parkinson’s disease are other causes of ABI which are often forgotten in discussions of brain injury. Nevertheless, Fortune and Wen (1999: 57) comment that they “are important causes of ABI, particularly in older people.” The epidemiology of brain injury in Australia is quite different to some other countries, such as the United States. In the USA, the level of firearm-related brain injury is much higher.

These brain injuries caused by firearms are not evenly distributed throughout the population—African Americans have a much higher rate of this sort of brain injury than other community groups (Thurman, Alverson, Dunn, Guerrero and Sntezek, 1999).

EFFECTS OF A BRAIN INJURY

Higgenbottom (1998) suggests that the effects of a brain injury can most usefully be divided into four types: cognitive, perceptual, physical and behavioral/ emotional. Although such categories are somewhat arbitrary, I have chosen to adopt them because they are useful in understanding the extensive effects of a brain injury. I will, however, add one additional category: psychosocial effects. This category is important because of the social isolation which often accompanies brain injury. I will now summarize what the literature says about the effects of a brain injury. These effects are so significant they have been likened to "the Titanic revisited" (Dell Orto and Power, 1994).

Cognitive Effects

In their summary of the literature on the cognitive effects of a brain injury, Ownsworth and Oei (1998) identify the following types of effects: problems with attention and concentration, memory problems, trouble with planning and organization, difficulties with initiation and follow-through, slowness in thinking and performance, confusion, problems with awareness of deficits, and paranoid ideation. People with a brain injury often have difficulty processing information and require more time to process things due to changes in their speed of cognition (Zhang, Abreu, Masel, Scheibel, Christiansen, Huddleston, and Ottenbacher, 2001). Also, people with a brain injury take longer to regain attention after they have been distracted than non-injured people (Bate, Mathias and Crawford, 2001; Chan, 2001; Whyte, Schuster, Polansky, Adams, and Coslett, 2000). As a result, it is important to provide environments which are less distracting and to establish an environment where people with a brain injury feel comfortable working at their own pace.

Impaired awareness is a common characteristic of people with a brain injury (Boake, Freeland, Ringholz, Nance, and Edwards, 1995; Gasquoine and Gibbons 1994; Priganto, 1996; Schlund, 1999; Sherer, Boake, Levin, Silver, Ringholz, and High, 1998). Some people may be completely unaware that they have experienced a brain injury, while others admit some problems but fail to fully appreciate all the effects of their brain injury. Flashman, Amador and McAllister (1998) suggest that up to 45% of individuals with a moderate to severe traumatic brain injury have reduced awareness of their "deficits." Trudel (1996) relates this impaired awareness to the person's distractibility and perseverative responses. Reduced awareness can mean people may not realize they have made social indiscretions and can experience difficulties assessing their own abilities and impairments. It can also mean that people are less motivated to participate in rehabilitation programs (Sherer, Bergloff, Boake, High and Levin, 1998). Because of diminished awareness, people with brain injuries may demonstrate certain forms of behavior such as aggression, impulsivity, disinhibition and impaired cognitive functioning (Manchester, Hodgkinson and Casey, 1997). Apathy is another common result of brain injury (Kant, Duffy and Pivovarnik, 1998).

Many people with a brain injury also face difficulties with everyday planning and organizing. Although their intellectual abilities are often unaltered, they often lack the executive functions which would allow them to plan and organize activities. Such difficulties are often closely related to damage to the frontal lobes, which are the parts of the brain that help a person plan activities. Kay (1994: 9) suggests that people with this problem often have a "flat affect," meaning that the person seems to have lost their motivation, drive and spontaneity. People with planning difficulties often have problems with initiation and follow-through.

Perseveration is another common effect of brain injury (Hotz and Helm-Estabrooks, 1995). Cohen and Dehaene (1998: 1641) define perseveration in the following way:

> Perseveration consists of the inappropriate repetition of a preceding behaviour when a new adapted response is expected.

Perseveration seems to be related to attention and memory problems, as well as disordered motor patterns (Vaughan, Agner and Clinchot, 1997). Cohen and Dehaene (1998: 1641) distinguish between three types of perseveration: "stuck-in-set" which means a person cannot switch from one task (or response) to another; continuous perseveration, where a person compulsively repeats certain elementary motor patterns (such as drawing a series of loops instead of a circle); and recurrent perseveration, where a previous response is repeated to new stimuli (such as continually repeating the same word when provided with new objects to name). Perseveration is commonly associated with frontal lobe injuries (Amos, 2000; Joseph, 1999; Tate, 1999). In one recent study, one third of people with brain injuries arising from right hemispheric stroke displayed preservative behavior (Na, Adair, Kang, Chung, Lee, and Heilman, 1999).

Some people with a brain injury may also experience psychiatric illness, including paranoia. Indeed, one estimate is that somewhere between 56% and 69% of people with a brain injury have a psychiatric illness (Luiselli, Arons, Marchese, Potoczny-Gray, and Rossi, 2000). There have been a number of studies which have investigated the association between paranoia and brain injury, including Achte, Jarho, Kyykka, and Vesterinen (1991), Bloom and Kraft (1998), Weinstein, Woodard and De Silva (1998), and Young, Robertson, Hellawell, de Pauw, and Pentland (1992). People experiencing such paranoia can blame others for their condition, are mistrusting and suspicious, and are often afraid of being deceived. Paranoia is not the only form of psychiatric illness which is associated with brain injury. Head injuries increase the risk of schizophrenia-like psychosis (Sachdev, Smith and Cathcart, 2001). Harvey and Bryant (1998) also found that many people with TBI experience post-traumatic stress, a finding confirmed in studies by Bryant, Marosszeky, Crooks, Baguley Gurka (2000) and Friedland and Dawson (2001). Childers, Holland, Ryan, and Rupright (1998) also suggest that there appears to be an association between organic head injuries and obsessive-compulsive disorders. However, these findings conflict with another study by Coetzner, Stein and Toit (2001) which suggests there is no support for such a connection.

Perceptual Effects

Persistent communication problems are also seen as a serious and common effect of TBI (Galski, Tompkins and Johnston, 1998). Closed head injuries frequently lead to language deficits, particularly communication problems in everyday situations (Hinchliffe, Murdoch and Chenery, 1998). People with traumatic brain injury often have difficulty finding the right words and have difficulty expressing ideas clearly (Tucker and Hanlon, 1998). Aphasia (an inability to use or understand words) and dysarthia (a speech disorder) are a common result of brain injury (Murdoch, 1990). Decreased verbal output is also associated with lesions in certain areas of the brain (Walsh, 1985: 161). McDonald and Pearce (1995) also found that when communicating, people with closed-head injuries were more likely to produce less essential information and more unnecessary information than people without a brain injury. Brain injury has also been associated with language impairment and problems with normal speech (Campbell and Dollaghan, 1995; Stierwalt, 1997). People with a closed head injury often have a significant impairment of lip and tongue function, which can affect speech and communication (Theodoros, Murdoch and Stokes, 1995).

Manzi and Weaver (1987: 35) list seven common communication problems following brain injury:

1. Reduced auditory comprehension.
2. Reduced reading and visual comprehension.
3. Nonsensical expressive language.
4. Irrelevant comments.
5. Lack of verbal inhibition.
6. Inappropriate ordering of words and inappropriate grammar.
7. Inability to recall/remember words.

Recent studies of brain injury in children indicate that the effects may even be more extensive than suggested by Manzi and Weaver. Trudeau, Poulin-Dubois and Joanette (2000) suggest that communication problems following brain injury may occur at a number of levels simultaneously, including lexical-semantic, written, cognitive-linguistic, discourse and pragmatic skills.

Mid-frequency hearing loss is a common effect of brain injury (Scott, Bauch and Olsen, 1999). It has been estimated that approximately 56% of people with brain injuries experience some degree of peripheral hearing loss after their initial injuries, but only 14% have permanent hearing loss (Griffiths, cited in Lubinski, Steger- Moscato and Willer, 1997: 104). However, certain sub-sections of the ABI population have higher rates of hearing loss. For instance, one study by Sabin, Lee and Har-el (1998), which focused on traumatic brain injuries caused by low-velocity gunshot wounds, found 69% of their sample experienced otorrhoea and 65% experienced hearing loss. Also, 89% of people with a brain injury studied by Jury and Flynn (2001) reported an intolerance to loud or sudden noises. Over half the sample studied by Jury and Flynn (2001) also reported tinnitus.

Communication difficulties may also be exacerbated by cognitive impairments. Hornak, Rolls and Wade (1996) found that people with frontal lobe damage tended to experience difficulties identifying facial and vocal emotional expressions.

Physical Effects

A brain injury not only causes cognitive problems, but can also create difficulties with voluntary and reflexive motor behaviors. For instance, Haggard, Cockburn, Cock, Fordham, and Wade (2000) report that people with TBI often talk slowly, walk with an ambling gait, and have exceptional difficulties in coordinating their arm, hand, leg, and foot movements. Ochi, Esquenazi, Hirai and Talaty (1999) confirm that people with a TBI tend to walk slower than the normal population. Levander and Sorrenson (1998) also found that people with moderately severe head injuries displayed subtle motor and language deficits, while Collazo (1995) states that closed head injury results in slower hand and eye reaction and movement times. Fasotti and Kovacs (1995) also suggest that slow information processing is one of the "deficits" of brain injury that does not resolve completely.

Swallowing can also be a major problem for people with a severe brain injury. It is common to see people with a severe brain injury who have dysphagia and aspiration problems (Leeder, 1999). Swallowing disorders often mean that the oral intake of food is greatly affected. People who swallow abnormally take longer to start eating and to achieve total oral feeding and their recovery can be compromised by the lack of nutrition (Mackay, Morgan and Bernstein, 1999). Breathing can also be affected in people with a brain injury—79% of people with a brain injury studied by McHenry (2001) had moderate problems with expiration. Also, there is a high risk of respiratory disturbances in people who have had a tracheotomy. A study by Keren, Cohen, Lazar-Zweker and Groswasser (2001) suggested that as many as 45% of people who have a tracheotomy following a brain injury experience respiratory disturbances.

Seizures are quite common in the first week following moderate or severe head injuries. Neumann (1995: 107) suggests these should not be termed epilepsy, although they do substantially increase the risk of post-traumatic epilepsy. Perron, Brady and Huff (2001) also argue that these seizures are not strictly epilepsy because they are simply an expression of loss of cortical inhibition. However, there is some evidence to suggest that people with severe traumatic brain injuries have a higher long-term rate of epilepsy than the general population (Singer, 2001).

Long term daily living skills require a range of physical, cognitive and perceptual skills which are frequently damaged as a result of head injury (Calvanio, Burke, Kim, Cheng, Lepak, Leonard, Dwyer and Gavande, 2000). Dawson and Chipman (1995) suggest that over two-thirds of people with TBI require assistance with daily living activities. As well, many people with a brain injury experience sleep disorders which make it harder to function in everyday situations (Quinto, Gellido, Chokroverty and Masdeu, 2000).

Behavioral/Emotional Effects

The literature has also highlighted many of the personality changes associated with brain injury. Ownsworth and Oei (1998) identify the following personality changes associated with a brain injury: increased irritability and aggression, poor social judgment, inappropriate behavior, impulsivity, emotional lability, mood swings, inappropriate emotional expression, apathy, suspiciousness/paranoia, disinhibition, loss of ability to show empathy and catastrophic reactions. Many of these behaviors affect not only the individual with a brain injury, but also their family and others.

A combination of aggression, impulsivity and disinhibition is a very common result of brain injury, especially among people with frontal lobe injuries (Grafman, Schwab, Warden, Pridgen, Brown and Salazar, 1996). Diminished problem-solving abilities can also contribute to increased aggression and violence (Greve, Sherwin, Stanford, Mathias, Love, and Ramzinski, 2001). Anger management issues have particularly been reported among offenders with a brain injury (Turkstra, Jones and Toler, 2003). Indeed, such behavior has been labeled "acquired sociopathy" (Blair and Cipolotti, 2000). However, a more constructive term is "challenging behavior." Yody, Schaub, Conway, Peters, Strauss and Helsinger (2000) use the term "challenging behaviour" to refer to a range of activities, including aggression, social withdrawal, disinhibition and self-harming activities. Yody et al. (2000: 1041) choose this term because they want to stress that such behavior, "no matter how difficult, has function, purpose, and meaning for the individual." Challenging behavior may occur because people with a brain injury are more likely to firmly believe that their memory is correct in circumstances where it is actually mistaken (Robertson, Manly, Andrade, Baddeley and Yiend, 1997).

People with a brain injury are often described as having "behavioral problems" such as physical or verbal aggression, self-injury and property destruction (Rothwell, La Vigna and Willis, 1999). Inappropriate tears or laughter, irritability, and over-reaction have also been identified as significant behavioral issues in people with a brain injury (Gronwall, Wrightson and Waddell, 1998). A major part of these problems seems to be that people with a brain injury have a different sense of what is and what is not acceptable behavior and have difficulty regulating their own emotions, and realizing that they are transgressing social norms. Accordingly brain injured people may have completely different perceptions of events compared to people without brain injuries.

Poor social judgment, including inappropriate social and sexual behavior, is a common effect of brain injury. Such behavior can include inappropriate touching as well as aggressive outbursts. Difficulty with social self-regulation, and difficulty inhibiting impulsive behaviors in public, is common in frontal and temporal lobe damage (Dombovy, 1998). Winslade (1998: 90) suggests that such changes are so profound that they often lead family members to make comments like "He is not the man I married" and "It is like living with a different person." Common changes in this regard include childishness, egocentricity and reduced tact.

Findings of depression following a brain injury are also common. More than half of the people studied by Garske (1990) indicated long-term lower self-esteem and mild to severe depression. In their study, Douglas and

Spellacy (2000) found that 57% of people with a severe traumatic brain injury were showing significant signs of depression. Over 40% of people with a brain injury studied by Kreutzer, Seel and Gourley (2001) could be classified as having experienced a major depressive disorder. León-Carrión, De Serdio-Arias, Cabezas, Roldán, Domínguez-Morales, Manuel Barroso Y Martín and Sanchez (2001) found 65% of people with a traumatic brain injury were at clinical risk to commit suicide. Likewise, studies by Satz, Forney, Zaucha, Asarnow, Light, McCleary, Levin, Kelly, Bergsneider, Hovda, Martin, Namerow and Becker (1998) and Satz, Zaucha, Forney, McCleary, Asarnow, Light, Levin, Kelly, Bergsneider, Hovda, Martin, Caron, Namerow and Becker (1998) also found that people with more severe head injuries were likely to suffer depression. Kim and Choi-Kwon (2000) suggest that depression is more likely in stroke survivors whose lesions are nearer to the frontal lobe. Such mood changes are often an effect of changes in chemical neuroanatomy.

The loss of the ability to show empathy may be another significant result of brain injury. Eslinger (1998: 193) suggests that changes in a person's ability to show empathy are especially evident after prefrontal cortex and frontal lobe injuries, and can have significant effects on a person's family, work and social life. Grattan and Eslinger (1989) also suggest that a lack of empathy following brain injury may also reflect compromises in cognitive flexibility. They suggest that cognitive flexibility is a prerequisite for empathy and a brain injury may prevent such flexibility.

Long-term problems in sexual function have also been found amongst high numbers of people with TBI (Gronwall, Wrightson and Waddell, 1998). Aloni, Keren, Cohen, Rosentul, Romm and Groswasser (1999) suggest that while problems with intimacy may not occur in the short-term, significant long-term difficulties in interpersonal relationships and intimacy in marital relationships are common. These difficulties are often the result of personality changes, depression, guilt, role alterations, egocentrism, reduced social outlets, and changes in sexual contact. Kravetz, Gross, Weiler, Ben-Yakar, Tadir and Stern (1995) also found that people with a brain injury often have reduced self-esteem which can lead to stresses in a marriage.

Psychosocial Effects

Many people with a brain injury experience social isolation following their release from hospital. In their study of 208 people released from the Brisbane Brain Injury Rehabilitation Unit between 1991 and 1995, Doig, Fleming and Tooth (2001) found that the vast majority of people had "poor" levels of community integration. Loneliness is therefore common for people with a brain injury. Unemployment is also common—Kersel, Marsh, Havill and Sleigh (2001) found an unemployment rate of approximately 70% in one group of brain injury survivors. A return to driving is also difficult, due to problems with aggression, memory, epilepsy, and vision. In the first year after the injury, the majority of people with a severe brain injury do not return to driving (Hawley, 2001).

Many people with a brain injury have contact with the criminal justice system because of violent or aggressive behavior (Feeney, Ylvisaker, Rosen and Greene, 2001). Misidentification, often associated with problems in facial recognition and delusions, may also lead people with a brain injury to act in a violent or aggressive manner (Silva, Leong and Wine, 1993).

This section of the chapter has described in detail the effects of brain injury on a person's functioning. For most people with ABI, there is significant contact with the health system at various points in the post-injury process. The next section of the chapter discusses how the health system responds to the challenge of a brain injury.

RESPONDING TO BRAIN INJURY

This section of the chapter will now examine responses to brain injury. It will discuss the Intensive Care Unit, the Rehabilitation Team, attempts to gain objective measures of the brain injury, and the process of rehabilitating brain injury survivors so they can "compensate" for their "deficits."

Intensive Care Unit

The benefits of the medical model are never seen more clearly than in the Intensive Care Unit (ICU). It is in ICU that many lives are saved. Family members often report being distressed by seeing many tubes hanging out of an unconscious person's body, but the complex (and sometimes unpleasant) procedures of ICU play an integral part in medicine's initial response to brain injuries. In ICU, the person with the brain injury is usually unconscious or heavily sedated. They often have a nasogastric tube, an endotracheal tube, a respirator, a chest tube for drainage, IV Fluid on a drip, and a urine drainage container. EKG electrodes are also commonly attached to the unconscious person. Tracheostomy tubes may also be necessary. Tracheostomy tubes are used if a person cannot breathe on their own, cannot cough up foreign particles and thick mucus, and cannot prevent food and drink from entering the lower airway (Butler, 1994: 45).

While the person with the injury is unconscious, it is usual practice in most hospitals for the family to be provided with a range of information about what it means to be in a coma and to have a brain injury. The unconscious person is also given a range of tests and is continually monitored for signs of deterioration or improvement. A limited number of family members are allowed to sit beside the unconscious person in ICU. This is a frightening, confusing and upsetting time for family members, as the person's fate is often uncertain.

Snow and Ponsford (1995: 34) suggest that the members of the treating team should be very careful in their communication about the injured person:

> Staff should not discuss, in the presence of the injured person, any negative views regarding prognosis. The need for consistency in the information conveyed by team members cannot be overemphasised. Because this information is both complex and emotionally charged, inconsistencies merely perpetuate confusion, and do little to engender trust in the expertise of the treating team as a whole.

Measuring the Brain Injury

A range of techniques may be used to assess and monitor the person who is in a coma or who is emerging from a coma. These tests look for "objective" measures of brain injury and include the Glasgow Coma Score, CT scans, MRIs, PET scans and SPECT scans. As the person emerges from a coma, there are also a number of diagnostic scales which have been developed in order to measure improvements in consciousness. These include the Coma Recovery Scale, Sensory Stimulation Assessment Measure and the Coma-Near Coma Scale, among others (Snow and Ponsford, 1995). In the longer term, if the person becomes conscious, he or she may have neuropsychological assessments such as the Overt Aggression Scale and the Mayo-Portland Adaptability Inventory. Other tests such as the Functional Assessment Measure and the Functional Independence Measure may also be administered (Hall, Hamilton, Gordon and Zasler, 1993).

Rehabilitation

The need for a "rehabilitation team" to address the difficult issues associated with brain injury is a consistent theme in the literature. Griffiths (1997), Gronwall, Wrightson and Waddell (1998), and Powell (1996) all state that these teams include nurses, doctors, physiotherapists, occupational therapists, psychologists, social workers and speech therapists.[1] Rehabilitation following brain injury is based on the idea that people with a brain injury should "compensate" for their "deficits," regulate their behavior and act in more socially acceptable ways. A great deal of rehabilitation aims to ensure that the abnormal/pathological behaviors and personal "defects" of people with a brain injury are identified, treated and overcome through medication, behavior modification therapy and other techniques. Medical and allied health professionals play a key role in this process, as Gordon and Hibbard (1991: 13) comment:

> . . . a constellation of procedures are applied by a trained practitioner (usually a neuropsychologist, speech language pathologist, or occupational therapist) to provide brain-injured individuals with skills and strategies needed to perform tasks that are difficult or impossible for them, due to the presence of underlying cognitive deficits.

Bell and Tallman (1995: 319) conclude that people with a brain injury commonly experience delayed recovery and that prolonged, intensive rehabilitation may be necessary.

Nursing Homes for the Least Responsive

When medical practitioners decide they can do no more for a person with the brain injury, but the person has not regained sufficient function to live in the community, he or she may be sent to an aged care nursing home. In fact, brain injury survivors are more likely than any other group of disabled people in Australia to be sent to aged care nursing homes. Moylan, Dey and McAlpine (1995) conducted a survey of 811 aged care facilities in Australia and found that 52.8% of younger people in nursing homes had a brain injury or neurological impairment. This research was consistent with an Australian Bureau of Statistics (ABS) study which found that people with ABI were four times more likely than other disabled people to be living in health, aged care, or disability support establishments (ABS, 1993). The reason why brain injury survivors are sent to these institutions is because the medical model is seen to have exhausted its potential, the person has not recovered, and an institutionalized life is considered the only appropriate solution. Medical literature is eerily silent on the quality of life which people in this situation experience.

EXAMINING THE UNDERLYING THEORY—THE MEDICAL MODEL

Studies of brain injury are so diverse in their focus, methodologies and audience that it is difficult to characterize the literature as a whole. However, the literature on brain injury has been dominated by medical and allied health professionals, and particularly by one way of viewing impairments, namely the medical model of disability. Major international journals such as *Brain Injury, The Journal of Head Trauma Rehabilitation* and *Neurology* consistently provide an outlet for recent academic work in the field by health professionals. Accordingly, there is an abundance of work on brain injury by psychologists, neurologists, physicians, neurosurgeons, and so on. Major themes from the medical model include: the assumption that it is possible to accurately diagnose an impairment; the perceived need for a team of health professionals to control the process of recovery; the promotion of rehabilitation as a way of teaching disabled people how to "compensate" for their "deficits"; and the assumption that social disadvantage stems from an underlying pathology. I shall now examine some of these assumptions in more detail.

Six major assumptions underlie the medical model, according to Petersen (1994: 15). These assumptions are:

1. People do not normally demonstrate the symptoms of ill health.
2. People become ill because of a deviation from a biological norm.
3. Emotional or physical changes make people aware that something is wrong.
4. People seek medical help if symptoms persist.
5. People will be accurately diagnosed by a doctor, and assured that there is nothing wrong, when appropriate.
6. Doctors will prescribe an effective remedy and patients will recover and be cured.

Other related assumptions identified by Petersen include: the presumption that individuals make autonomous decisions about their health; the presumption that people are able to recognize symptoms and make informed choices about how to respond, who to see and how to find that person; and the assumption that curing disease is more important than preventing it.

Petersen stresses that medical discourse is not interested in what might exist, or what patients subjectively experience, it is only interested in what is the observed situation. This focus on observable phenomena has meant that a great deal of effort is expended trying to identify and label abnormal anatomical and physiological processes. The sorts of "scientific" investigation techniques which doctors use to establish a patient's pathology are observation, examination, experimentation and tests. Medical practice is based on methods that are objectively verifiable and replicable. Such a methodology is designed to establish the specific aetiology of a disease. It is assumed that there is a biological universality unaffected by time, space or culture (Davis and George, 1993: 159). Every disease is assumed to have a specific causal agent that has affected the physical body. Science-based medicine reduces illness to mechanical processes (Clarke, 2001). It identifies toxins, microbes and bodily malfunctions. It implies that disabled people's exclusion is caused by biological (rather than social) limitations (Sherry, 1999). The techniques of medicine used to identify these pathologies involve skilled diagnosis and interventions aimed at correcting biological abnormality.

The widespread influence of positivism means that medicine traditionally responds only to observable entities known directly to experience (Petersen, 1994: 17). Indeed, Bickenbach (1993) states that this model assumes, without argument, that disability can be measured according to objective scientific investigation. Medicine is seen as a repository of "truth," where neutral experts make objective and sometimes final decisions on health and illness matters, and maintain exclusive rights to perform surgery and prescribe drugs. Power lays in the hands of skilled experts, principally doctors, rather than the individuals with the impairment.

The focus of the medical model on the experience of impairment is useful in terms of highlighting risk-factors which may make a person more likely to experience certain impairments. For instance, the epidemiological data outlined above helps us to understand that younger people are more likely to experience Traumatic Brain Injuries than older people. This information can be very useful in prevention campaigns. But often the social factors which help produce impairment (for instance, gender power differentials which lead to domestic violence and large numbers of women receiving traumatic brain injuries as the result of assaults) are ignored in the medical model. For this reason, some critics have called for a "sociology of impairment" to flesh out the role of social factors in the production of impairment (for instance, Hughes and Patterson, 1997).

CRITICISMS OF THE MEDICAL MODEL

While the medical model is universally approved in acute care when it saves lives, its long-term influence over the lives of disabled people, including brain injury survivors, has been criticized by disability activists. Their criticisms generally revolve around four main areas:

- The failure of the medical model to consider impairment in its social context, including medicine's role in that social context;

- The fault-finding and disempowering approach which dominates medical practice;
- The failure of many medical practitioners to oppose segregation, which is criticized as an improper ethical position; and
- The problematic regimes of normalization embedded in medical discourse.

Failure to Consider the Social Context

Medicine adopts an individualistic approach to health care which ignores many of the social dimensions that create impairment and determine its effects. It is essential however to recognize that brain injury has important social dimensions. Brain injury is not randomly distributed throughout the population. The incidence of brain injury is connected to social position. A small, but growing number of studies has shown that people from lower socioeconomic backgrounds experience higher rates of many of the direct causes of brain injuries, such as:

- motor vehicle accidents (Lawson and Black, 1993; McMichael, 1985);
- pedestrian injury (Stevenson, Jamrozic and Burton, 1996; Stevenson, Jamrozic and Spittle, 1995);
- physical abuse (Ryan, Davis and Oates, 1977; Vinson, Berreen and McArthur, 1989);
- near-drowning (Nixon and Pearn, 1978);
- accidents other than traffic crashes (Lawson and Black, 1993);
- stroke (Bennett, 1996); and
- coronary and ischaemic heart disease (Bennett, 1996; Burnley, 1998; Dobson, Halpin and Alexander, 1991; Gibberd, Dobson, Florey and Leeder, 1984; Leeder, Gibberd, Dobson, and Lloyd, 1984).

Other important factors in the social production of brain injury include gender, ethnic minority status, age and a history of substance abuse (Wagner, Sasser, Hammond, Wiercisiewski and Alexander, 2000).

The links between gender and brain injury are under-researched. However, there is some literature which documents the high rate of brain injuries stemming from abuse and domestic violence. For instance, in their study of women in domestic violence shelters, Monahan and O'Leary (1999) found that 35% of women had experienced a head injury at the hands of their partners. Likewise, Corrigan, Wolfe, Mysiw, Jackson, and

Bogner (2003) studied 169 women with health problems directly related to domestic violence and found that 30% of the women had at least one experience of unconsciousness from battery, and 67% of women reported residual problems that were potentially head-injury related. These findings indicate the importance of feminist work around preventing domestic violence for this population, bur also indicate that increased disability awareness is necessary in domestic violence shelters.

Medicine's failure to consider the social context which produces brain injury means that its responses are often extremely narrow and individualistic. Medicine has not only failed to consider the social production of brain injury, it has also failed to consider the importance of social responses to brain injury. Bickenbach (1993: 25–35) argues that medicine assumes that people with impairments do not participate fully in society because of their individual physical, sensory or psychological limitations. Such an approach has been criticized for ignoring the impact that the physical and social environment can have on a person's capacity to participate fully in society (Barnes, 1991). A consequence of adopting this perspective has been identified by Linton (1998b: 11)—the individual is positioned as having a "personal" problem requiring medical treatment. Rather than recognizing that the person experiences social barriers, the person is "treated." In this way, those practices which prevent the individual from having a full and rich life are assumed to be permanent and irrevocable. That is, medicine spends so much energy focusing on the impaired mind or body that it tends to forget that some environments can be more "friendly" than others for impaired people. Many disability activists focus their energies on making environments more accessible, but medicine seems to ignore this social context and focuses simply on the individual body of an impaired person.

Oliver (1986: 6) suggests that medicine's treatment of disability as a personal tragedy is based on a questionable assumption—the assumption that disabled people do not participate fully in society because they have individual physical or psychological limitations. This questionable assumption underpins the literature on ABI and is the reason it has not examined the social restrictions experienced by people with a brain injury. Concepts of social exclusion and disability oppression are insufficiently integrated into the responses of the medical model. Because the focus is on the "defects" of the individual, inadequate attention is often paid to the economic, social or physical barriers which may prevent them from participating more fully in community life.

One of the major cultural responses to impairment is to regard it as a personal tragedy (Oliver, 1990, 1996). Medicine has played an important role in the creation of this discourse, for instance, by describing a person with a brain injury as a "victim" of a "tragedy." Griffiths (1997), Powell (1996) and Winslade (1998) all suggest that the tragedy has ripple effects throughout the family of the "victim." But as Linton (1998b: 5) suggests that rather than experiencing disability as a completely negative experience and a loss, narratives from the disabled community recount it in far more complex ways. For instance, disabled people find creative ways to understand atypical experiences, share stories of adapting to a world configured for non-disabled people, find one another and identify and name disability in a world reluctant to discuss it, and unearth historically and culturally significant material which is relevant to our experiences.

A Fault-Finding and Disempowering Approach

The medical model is portrayed as being based on scientific neutrality, but it has been criticized for creating a particular fault-finding and disabling perception of an individual with an impairment. The medical model has a penchant for labeling and pathologizing every element of difference within impaired bodies. It has been suggested that the process of labeling and highlighting all of the "defects" of an impaired person devalues the person, so that society (and the individuals themselves) often become obsessed with the differences which lay within impaired bodies, differences which are negatively valued and regarded as tragic (Stone 1995; Sullivan, 1991). Baird (1992: 5) suggests that the obsession of doctors with the need to label and treat various "abnormal conditions" can mean that they are the least well equipped to treat people with disabilities with respect or listen to their real needs.

The medical model often fails to recognize that a diagnostic label can attach a stigma which may be incredibly harmful for a disabled person. Lonsdale (1990) argues that when doctors give a diagnosis, the clinical label attached to them serves two distinct functions: it legitimates their needs for the purposes of administering social welfare and rehabilitation assistance; but it attaches a stigma to that person. Such a stigma may also foster a false sense of helplessness and dependence because it promotes a perception of disabled people as "passive, dependent, powerless, and requiring non-disabled people to do things for them" (Munford and Sullivan, 1997: 18).

Even when people with an impairment have no medical problems and their lives cannot be improved by medical intervention, health professionals still retain an amazing amount of power over them because of their role as gatekeepers over assistance with housing, employment, education and welfare issues (French, 1994a). Linton (1998a: 530) comments that such powerlessness flows inevitably from the medical approach to health issues:

> In reducing pain or impairment to something that needs to be 'fixed' and medicine as the remedy to that stated problem, medicine succeeds in cornering the market on knowledge about these phenomena.

Like Linton, many authors argue that by distinguishing between the "experts" and the "patients," the medical model discounts the lived experiences of disabled people and gives them little opportunity to contribute to the analysis of their own situation (e.g. Brisenden, 1998; Heron, 1981; Oliver, 1990). Thus, disabled people are often placed in a position where they either have to struggle with health professionals for control over decisions which affect their lives or simply to accept dependency. Often, decisions about medical treatment need to be made with an individual's goals and strengths in mind and cannot just be based on medical criteria. Newell's (1999: 15) studies of the negative experiences of disabled people in the health system leads him to suggest:

> If you have got a disability, then don't get sick. If you get sick, then don't go to hospital. If you have to go to hospital, then make sure that you have as much control over your care regime as possible.

Newell stresses that instead of focusing on the "health" of a person, narrowly defined by a medical approach, it may be more appropriate to focus on areas of care which disabled people themselves identify. These areas are far more likely to lead to enabling life opportunities. In contrast to the enabling life opportunities envisioned by Newell, impaired people experience a relative lack of power and a loss of self-determination in the medical model—major health and welfare decisions are made by medical experts.

It is ironic that the medical model gives health professionals such power over disabled individuals given that the focus of medical intervention is usually on "curing" a disease and yet living with a disability identity is a long-term social state which cannot be cured. That is not to deny that there are impairments associated with temporary or intermittent disablement—but that many of the "symptoms" of disability cannot be alleviated through medical intervention. As Lonsdale (1990) comments, medical intervention for disabled people is usually limited to (and very useful in) the acute stages, but the individual and their family is usually responsible for the long-term management of the condition. In such circumstances, it does seem odd that medical practitioners are allocated such an important role in the medical model of disability. French (1994b: viii) also identifies the excessive power of medical practitioners as part of the problem:

> Disabled people have also been subject to the hostile and patronizing attitudes of non-disabled people, including health and welfare professionals and those who work for charities. They have been expected to play a particular role of passivity, gratitude, dependency and 'courage,' and have sometimes become inwardly oppressed by internalising these role expectations. Although the assistance health professionals can offer is not denied, they can also be viewed as part of the problem. Health professionals work within the power structures which control disabled people's lives and maintain them in their disadvantaged state. Professional education has rarely addressed disability from a civil rights perspective, but rather has chosen to view it as the personal problem of individuals who happen to have impairments.

Fulcher (1989: 44) goes further and argues that the medical model is the main opponent of people with disabilities because its claims of "professionalism" and "neutrality" inform the perceptions of politicians, social workers, psychologists, rehabilitation counselors, teachers, administers and many others who have informal power over people with disabilities.

Brisenden (1998: 22) makes a very amusing comment that reflects on the power dynamics between health professionals and people with disabilities. He outlines a fantasy where a group of disabled people are able to subvert the established power dynamics and interrogate a doctor, rather than vice versa. The disabled people are trying to "understand the stigma of a career in medicine, and the effects it has on family and friends." People ask the doctor a series of searching questions, which probably reveal little about the person. Brisenden (1998: 22) wryly concludes:

> I suspect that we would learn very little about the individual beneath the white coat, but the feeling of power might prove too irresistible to be ignored.

Unethical Stance Towards Segregation

The medical model has been used to support the removal of people with impairments from their communities and their placement in institutions, sheltered workshops and a range of other segregated institutions. Drake (1999: 69) suggests that there is a clear connection between the way disability is defined and power is distributed and medicine has played a key role in the legitimation of segregation. Many disabled people regard this as an unethical position for medicine to adopt, because the underlying message of segregation is that we are not equal, that we are less than human.

As Bowe (1978) argues, segregating disabled people away from society is simply an attempt to make them "invisible." Such removal of people with disabilities from the community may have been sanctioned by the medical model, but it has been likened to social apartheid by disability activists (Parsons, 1994). As Finkelstein (1991) has commented, there is something profoundly undemocratic about non-disabled people deciding to remove people with disabilities from the community. Miller and Gwynne's (1972) study of the Le Court Cheshire Home for disabled people suggested that such segregated institutions were designed to house disabled people while they moved from social death to physical death.

Medicine's Role in Regimes of Normalization

One of the most important insights in the work of Michel Foucault was the idea that regimes of normalization underpin a great deal of medical thought and practice. In *The Birth of the Clinic: An Archaeology of Medical Perception,* Foucault (1994: 34) makes this connection quite explicit:

> Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man,* that is, a study of *non-sick man* and a definition of the *model man.* In the ordering of human existence it assumes a normative posture, which authorises it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives.

Although Foucault's language in this passage is sexist (and in other places, his language is deeply disablist) the connection he makes between medicine and normalization is incredibly important. Foucault highlighted the importance of the medical gaze in terms of power and the body. The gaze, which he defines as the "act of seeing" (1994:ix) is central to the assessment of the body and its compliance with regimes of normality, but it also played an important role in disciplinary power more broadly.

This was a theme Foucault also explored in other works. For instance, in *Discipline and Punish: The Birth of The Prison,* Foucault (1995) highlights many of the medical, juridical, military, industrial, and pedagogical investments in the assessment and proscription of normality. He states that the medical supervision of diseases and contagions cannot be separated from other forms of disciplinary power, since they all establish a "political economy of detail" where power is directed at the body. The aim of setting up a disciplinary space, he argues:

> . . . was to establish presences and absences, to know where and how to locate individuals, to set up useful communications, to interrupt others, to be able at each moment to supervise the conduct of each individual, to assess it, to judge it, to calculate its qualities or merits. It was a procedure, therefore, aimed at knowing, mastering and using. Discipline organizes an analytical space.

Later in *Discipline and Punish,* Foucault (1995: 170) states:

> The success of disciplinary power derives no doubt from the use of simple instruments; hierarchical observation, normalizing judgement and their combination in a procedure that is specific to it, the examination.

In his later works, Foucault examined the implications of such power/knowledge regimes for individuals. For instance, in *The History of Sexuality Volume Three: The Care Of The Self,* Foucault (1986:43) highlights the social importance of the idea that a person should "take care of oneself," in terms of structuring the attitudes, behavior and ways of living of individuals. The care of the self is closely correlated with medical thought and practice, which Foucault's earlier work had shown were themselves deeply implicated in regimes of normalization. The power of medicine in this context of increased attention to the body was a serious concern to Foucault (1986:100):

> . . . medicine was not conceived simply as a technique of intervention, relying, in cases of illness, on remedies and operations. It was also supposed to define, in the form of a corpus of knowledge and rules, a way of living, a reflective mode of relation to oneself, to one's body, to food, to wakefulness and sleep, to the various activities, and to the environment. Medicine was expected to propose, in the form of regime, a voluntary and rational structure of conduct.

One of the innovative concepts which Foucault introduced in *The History of Sexuality: Volume One* was the notion of "biopower." Foucault focused his attention on what he called an "anatomo-politics of the human body" (1990:139). He also highlighted the power dimensions which underpinned "an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations, marking the beginning of an era of biopower" (1990:140).

Many disability studies scholars have relied upon Foucault's work in developing their own critiques of normalization. For instance in *Enforcing*

Normalcy, Lennard Davis (1995:128) states: “Normalcy, rather than being a degree zero of existence, is more accurately a location of bio-power, as Foucault would use the term.” Some disabled people feel that by portraying impairment as a pathology, defect, abnormality or dysfunction, the medical model contributes to negative social reactions towards impairment. It is sometimes suggested that the negative image of impairment developed in the medical model translates into cultural practices which regard people with impairments as somehow inferior, lacking or “not quite whole.” The dichotomy of normality and abnormality, which underlies a great deal of medical practice, is a key mechanism through which the bodies of people with impairments are devalued. Any departure by disabled people from the goal of “normality” is negatively-valued. Reflecting on this experience, Morris (1991: 28) states:

> The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our lives.

In America particularly, disability scholars have critically examined the “tyranny of normality” as a process of social exclusion (for instance, Baird, 1992; Davis, 1995; Russell, 1998). Indeed, “normality” and “abnormality” are value-laden terms which have an enormous power to harm. Linton (1998b: 24) suggests these concepts affect an individual’s most private thoughts about their worth, social position and acceptability because the association of disability with abnormality denies legitimacy to the experiences of disabled people. Similarly, Sullivan (1991: 271) comments:

> Together, the ideologies of individualism, medicalisation and personal tragedy theory constitute the hegemony which defines disability in capitalist society as the antithesis of normality, able-bodiedness and able-mindedness.

For disability activists, the problem is not that disabled people do not conform to an ideal of “normality” but that any departure from the goal of “normality” is negatively-valued. Dalley (1992) stresses that social conformity and the reduction of difference are often the core values behind attempts to “normalize” disabled people. So the focus on disability leads us to question the very essence of such categories as “normal” as opposed to the “pathological,” “insider” versus “outsider” and “competent citizen” as opposed to the “ward of the state” (Linton, 1998b: 2). This political message has often been delivered through art, drama and even humor. By critically examining oppressive definitions of "normality" which devalue disabled people, a thoughtful alternative is promoted, which acknowledges and values difference but does not rely on oppressive explanations to describe them (Abberley, 1989).

CONCLUSION

As a theoretical paradigm, the medical model has had an enormous effect on our understanding of, and response to, brain injury. It has profoundly affected the way the experience is perceived, it has led to the development of various "objective" measures which are intended to estimate the nature and effects of the injury, it has encouraged the promotion of medical "experts" in the make-up of the rehabilitation team, it has meant that brain injury survivors are pressured to "compensate" for their "deficits," and it has meant that the least responsive brain injury survivors are sent to nursing homes. Although the medical model has been very useful in illuminating the physical and cognitive changes associated with a brain injury, there is almost no literature on social experiences such as social isolation, loss of friends, loneliness, relationship breakup, and family problems—viewed from the perspectives of survivors. These issues, when framed within a disability studies perspective, connect to broader social justice issues such as social inclusion, exclusion and citizenship rights. Because of the dominance of medical ideas, the literature on brain injury tends to assume that our main concerns are our minds and bodies, rather than such wider social issues. Even then, being brain injured is assumed to be a fixed biological state rather than a social state which can be contested, denied, grappled with, and even celebrated. The collective, individual, and social struggles of brain injury survivors to have more influence over their own futures is also largely ignored within the literature. Brain injury survivors are silenced and their voices are unheard except when medical practitioners want to use their symptoms to illustrate a case study. In this way, the unique perspectives of survivors are lost amid a medically-dominated discussion. Our perceptions of the relationships, environments and structures which shape our experiences have been neglected. Our roles in defining what it means to be brain injured, contesting the labels we are given, and asserting our own views on the value of life after brain injury have barely been mentioned. To examine this area means moving from a focus on impairment to disability—and this is the aim of the next chapter.

This chapter has argued that the medical model can make an important contribution to our understanding of brain injury by highlighting the cognitive, perceptual, physical, and behavioral/emotional changes which may accompany a brain injury. But as a theoretical framework, the medical model is of limited value in considering the wider social experience of living with a brain injury in a disabling world. It also pays little attention to the social creation of impairment and this is a serious flaw. As well, because it focuses all its attention on identifying “defects” within the bodies of impaired individuals, the medical model has supported the existence of segregated institutions. For many brain injury survivors, even people who are still teenagers, this has meant a lifetime of incarceration in aged care nursing homes. Such a situation is a human rights injustice. The next chapter considers the social model of disability, which is seen by many disabled people to offer a vision of a world free from such injustice.

Chapter Three
Understanding the Disability

INTRODUCTION

In this chapter I will examine an alternative body of literature, which tends to focus on the social experiences of discrimination, marginalization and exclusion that many people with impairments experience. Whereas the medical model tends to focus solely on impairments, this alternative model, known as the social model of disability, focuses on social reactions to impairments. The chapter begins by discussing "What is Disability?" and by identifying disabling barriers. It then examines the effects of disability and considers various ways of responding to disability. The underlying theory behind the social model is then examined. Finally, some of the weaknesses of the social model are identified. The chapter highlights the important contribution which the social model can make to understanding the experience of disability, but also identifies a number of areas which have been under-theorized in the social model, such as the experience of embodiment, identity, and the operation of power.

WHAT IS DISABILITY?

The fact that the social and physical environment is unresponsive to the needs of people with impairments has been interpreted as a form of oppression by disability activists. The British group, the Union of Physically Impaired Against Segregation (UPIAS) was particularly influential in defining disability as a form of oppression:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.

> Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability' of people with such impairments. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no to little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPIAS, 1976: 14).

As this quote indicates, the initial definition of disability provided by UPIAS was aimed at people with physical impairments. It was later adapted to include other forms of impairment. The UPIAS definition of impairment and disability has become well known, partly due to the fact that a leading disabled academic, Mike Oliver, has consistently relied on them in his work (for instance Oliver 1983, 1990, 1996) but also because other academics have accepted these definitions (for instance, Drake, 1999; Priestley, 1999; Swain and Cameron, 1999). Key elements of this approach to disability are the distinction between impairment and disability, an argument that disability is a form of oppression, and an emphasis on the need to remove the barriers that prevent people with impairments from taking their rightful roles in society. The essential message is that although disabled people may have significant bodily, cognitive or psychological differences which distinguish them from non-disabled people, those differences do not justify inequality and should not deny us citizenship rights.

The basic premise of the social model has been summarized by Linton (1998a: 529):

> . . . society creates many of the problems disabled people experience and society has a responsibility to address them.

The social model is valuable because it draws attention to the barriers, discrimination, negative images and lack of opportunities which many disabled people experience. Barnes (1991) examined disabling barriers in detail and found that the human rights of disabled people are denied in a wide range of areas, including: the built environment, the labor market, education, welfare, health and support services, the media and the leisure industry. Barnes's research was consistent with Sutherland's

(1981) identification of discriminatory barriers in access to the built environment, as well as in employment and education. The social model has highlighted the fact that inaccessible environments prevent many people from fully participating in community life, and are inconsistent with demands for freedom and equality. Citizenship rights should not be dependent on being able to master the physical environment (Hahn, 1986).

Brisenden (1998) suggests that unless someone is bed-ridden or completely fatigued, the "most disabling" part of living with an impairment is the way society is organized. Through the material construction of society and the discriminatory attitudes of people within it, people who have impairments become "disabled":

> We are only people with different abilities and requirements, yet we are disabled by a society that is geared to the needs of those who can walk, have perfect sight and hearing, can speak distinctly, and are intellectually dexterous. If society was organized on a more equitable basis, many of the problems associated with not being physically 'perfect' (as if such a concept had any logical basis) would physically disappear.

Oliver and Barnes (1998: 21) agree that people with impairments are not always disabled in every context and suggest that it is impossible to identify the number of disabled people in a society. People are only disabled by an environment which does not meet their needs—this means that there is no fixed number of disabled people. This means that being 'disabled' or 'non-disabled' is not a static state—such categories are constantly being redefined, contested and transformed in social, political and institutional practices (Oliver and Barton, 2000). As Oliver (1999: 4) comments:

> . . . disabled people are not excluded from all societies. Accordingly exclusion is not an intrinsic part of the human condition of being disabled. Even in those many societies that do exclude disabled people, this exclusion varies with the economic and social conditions and the core values of the society concerned.

Access is fundamental to the construction (and contestation) of disability. As Sutherland (1981: 32) states:

> . . . there is a sense in which *all* the discrimination we encounter can be seen as being about access: access to an equal and unhindered role in the society of which we are a part.

Oliver (1990: xiv) goes so far as to suggest that experiencing such social restrictions and discrimination is a central part of the experience of disability for people with any sort of impairment:

> All disabled people experience disability as social restriction whether these restrictions occur as a consequence of inaccessible built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign language, the lack of reading material in Braille or hostile public attitudes to people with non-visible disabilities.

It is essential to recognize that breaking down barriers is not just about providing resources in alternative formats, or redesigning the built environment. It also entails redressing high rates of unemployment, providing real and valued employment opportunities and dismantling segregated institutions (Linton, 1998b). As well, it involves ensuring that disabled people have the same rights as other members of the community when it comes to matters of sex education, relationships and leisure opportunities (Drake, 1999).

Whereas the medical model implies that problems with access are caused by an individual pathology, the social model suggests that the unaccommodating nature of the environment is to blame. The politicization of access issues could therefore be seen as one of the great achievements of the social model. It has meant that environments can be clearly labeled as being hostile or friendly to people with impairments. The social model suggests that disability is not an individual trait, it is a social construction constantly made and remade through beliefs, practices, institutions, environments and behavior. In this vein, Higgins (1992: 8) states that "Disability is what we have made of physical, mental and emotional variation." The implication is that non-disabling environments and patterns of behavior can be developed—if disabled people have rights, support, recognition and self-determination (Sherry, 2000). Brisenden (1998: 25) argues that self-determination reinforces a person's sense of control and independence and is a reminder that medical concerns are only one aspect of the lives of disabled people. The British pressure group UPIAS (1976: 14) also strongly promoted the self-determination of disabled people:

> We reject the whole idea of 'experts' and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the psychology of impairment. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down

> to—far better than any able-bodied expert . . . (we) are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us . . . We look forward to the day when the army of experts on our social and psychological problems can find more productive work to do.

The social model has played a key role in the promotion of disabled people as the experts on their own lives and in assisting disabled people to gain the confidence to challenge disabling barriers. Instead of medical practitioners dominating our lives, the alternative is for disabled people to have control.

The social model has helped to politicize disability, so that it is seen as a form of oppression. Rob Imrie (1996), following the earlier work of Iris Marion Young (1990) on the nature of oppression, has identified five major dimensions of disability oppression: exploitation (disabled people being excluded from the labor force, or being "included" only in low skilled, low paid jobs); marginalization (such as experiences of discrimination in employment and a social security system which encourages dependency); powerlessness (reflecting a weak and dependent relationship with the labor market); cultural imperialism (the promotion of nondisabled values as if they were universal); and physical violence (which many disabled people experience as a daily reality in their lives). Imrie suggests that all of these dimensions of oppression need to be addressed in order to develop a society where disabled people will enjoy the same rights and privileges as other citizens. In Chapter Seven, when the work of the French theorist Michel Foucault is discussed, I shall problematize the theory of power which underpins such a concept of oppression. For the time being, however, I am prepared to simply outline this argument as an important dimension of the social model.

Positioning disability model as a form of oppression is a very different interpretation of the experience than is suggested by the concept of the "sick role" developed in the work of Talcott Parsons (1951). Parson's concept of a "sick role" suggested that "being sick" was as much a social role (excusing people from work for a short period of time) as it was a medical condition. This concept was useful in the 1950s because it challenged the biological reductionism of the medical model and suggested that disability and sickness constituted a specific social role. However, a number of flaws in Parsons' conceptualization of disability have been demonstrated. Marks (1999) points to five major conceptual errors in Parsons' work:

- It relies on a clear distinction between illness and health which cannot be empirically demonstrated;
- It fails to acknowledge the possibility of misdiagnosis and assumes that the doctor/patient relationship is characterized by consensus and cooperation rather than conflict;
- It fails to incorporate the roles of non-medical personnel in defining and treating illness;
- It does not accommodate the fact that many disabled people are not ill; and
- In practice, the rights and privileges associated with the sick role are not evenly distributed. Some groups of sick and disabled people (such as people with AIDS) are often blamed and stigmatized.

Given the flaws of the Parsonian position, it was not surprising to see that medical sociologists and disabled people turn their attention to other ways of conceptualizing disability. One such interpretation revolved around the concept of stigma.

Stigma is a concept developed and explored in the work of Irving Goffman (1961, 1963). Goffman argued that stigma was a deeply discrediting experience which separated certain groups of individuals from what he called "normals." Goffman believed that the experience of stigma meant that certain groups of people, including disabled people, homosexuals, people from different ethnic backgrounds and people with a "blemished character" such as criminals all have a "spoiled identity." Indeed, Goffman goes so far as to suggest that the only "unblushing American" is a "young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight and height, and a recent record in sports" (1963: 28). The focus of Goffman's work was on the interactions between these "normals" and the stigmatized individual. He highlighted many of the experiences of stigmatized people such as public staring, unwanted help and invasions of privacy. Goffman also discussed the techniques which certain individuals could use to manage their stigma. In this regard, he differentiated between the "discreditable" person who carried a non-visible stigma and the "discredited" person whose stigma was always visible. For the "discreditable person" the issue is:

> To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where (1963: 42)

Goffman did not conceive of the possibility of the stigmatized person rejecting the values of society:

> The stigmatised individual tends to hold the same beliefs about identity that we do; this is a pivotal fact (1963: 7).

So Goffman's work can be criticized for paying inadequate attention to the possibility that the stigmatized person could confront, reject, resist or ignore stigma.

For some time, stigma was the dominant theoretical framework through which disability was understood. Indeed, stigma continues to be a major focus of studies on disability today (for instance, Cahill and Eggleston, 1995; Ellis, 1998; Greil, 1991; Riddick, 2000; Susman, 1994; Taub, 1999; Wendell, 1996). However, despite this incredible influence, it is important to recognize that disability may be associated with stigma, but disability and stigma are quite different phenomena, conceptually and theoretically. A number of disability theorists (including Barnes, Mercer and Shakespeare, 1999 and Oliver, 1990) have criticized Goffman's arguments on the grounds that stigma is conceived as an individual attribute (rather than a form of social oppression) and that as a concept, stigma is so inclusive as to be virtually meaningless. Oliver (1990: 68) has highlighted the reasons why such a conceptualization of disability is unpopular:

> Disabled people have not found stigma a helpful or useful concept in developing and formulating their own collective experience of disability as social restriction. To begin with, it has been unable (so far) to throw off the shackles of the individualistic approach to disability with its focus on the discredited and the discreditable. In addition, its focus on process and interpersonal interactions ignores the institutionalised practices ingrained with social relations (in the sociological sense). And finally, therefore, they have preferred to reinterpret the collective experiences in terms of structural notions of discrimination and oppression rather than interpersonal ones of stigma and stigmatisation.

An interesting rebuttal to Oliver's arguments has been made by Watson (2003), who argues that Oliver's reading of Goffman is unfair and incomplete. Watson points out that Oliver's reading of Goffman essentially involves only two of Goffman's earlier books—*Asylums* (1961) and *Stigma* (1963), but ignores his later work, such as *The Presentation of the Self in Everyday Life* (1969), where Goffman explored the processes of negotiating a stigmatized identity in more detail. Nevertheless, the perceived limitations within the concept of stigma led to an emphasis on wider sociological processes which structure the experience of disability, and indirectly contributed to the development of the social model.

One important milestone in this regard was Robert Scott's classic study *The Making of Blind Men* (1969). Scott argued that blindness is a learned social role, rather than a biological fact: "blind men (sic) are not born, they are made" (1969: 121). Scott stressed the social nature of this role by pointing out that the vast majority of people who are classified as blind can actually see. Rather than being sightless, Scott presents these people as "sighted people who experience difficulty seeing" (1969: 43). The importance of socialization is evident because "blindness workers" are said to play a key role in the development of attitudes, behaviors and emotions associated with being blind. In effect, Scott argues, these workers teach their clients how to behave like "blind people."

Vic Finkelstein, a disabled man who had been expelled from South Africa because of his opposition to the Apartheid regime, and Paul Hunt, another disabled man who had been institutionalized because of his impairment, were disability activists who refined these ideas into a more concrete opposition to the "disabling society." Hunt used his own personal experiences as the basis for his writing—and in the process developed an understanding of life with an impairment which fundamentally challenged the association of disability with tragedy and the devaluation of difference through rigid conceptions of normality. Equally importantly, he argued that disabled people commonly experience stigma, prejudice, discrimination and oppression (Hunt, 1966). Finkelstein agreed that disabled people were oppressed, and likened the treatment of disabled people to Apartheid. Both Hunt and Finkelstein threw themselves into the emerging disability movement, and the involvement of such passionate and articulate disabled people presented a powerful challenge to the cultural stereotypes of disabled people as passive, tragic and dependent.

Finkelstein's *Attitudes and Disabled People* (1980) was the first attempt to demonstrate that the position of disabled people reflected wider economic relationships within capitalist society. He argued that the current situation of disabled people was the result of three stages of economic development. In Phase One, which corresponded to the era before the Industrial Revolution, the economy relied on agriculture and small industry, so it did not exclude disabled people from employment opportunities in the way that capitalist economies have done. Disabled people were simply a part of a larger underclass. However, in Phase Two, the era of capitalist society, disabled people were separated from their class origins and became a special, segregated group. Finkelstein suggested that the emergence of capitalism saw disabled people segregated into institutions because they could not contribute efficiently to the new economic order and he predicted that a new style of society was now developing. He labeled this development "Phase Three" and suggested that new technology was creating opportunities for disabled people, alliances were developing between disabled people and professionals, and disability was coming to be seen solely as a social restriction. Under these conditions, the liberation of disabled people was imminent.

There were many problems with the way Finkelstein conceptualized the relationship between disability and economic development. Primarily, these problems revolve around the way Finkelstein relates the position of disabled people in society to the economic base upon which that society operates. A simplistic, uncomplicated relationship between the mode of production and the experience of disability is assumed to exist: such experiences are expected to reflect, almost mechanically, the development of the capitalist system. Such an argument is essentialist and determinist; there is no emphasis on human agency. Cultural and political developments, including resistance by disabled people and their allies, are ignored in Finkelstein's search for overarching economic determinants in the history of disability. Oliver (1990: 29) has been critical of two elements of Finkelstein's analysis: its crude assumptions about the relationship between disability and the mode of production, and its simplistic assumptions about the liberating power of technology. Nevertheless, Oliver suggested that Finkelstein's argument was of "considerable value in highlighting the importance of the mode of production in significantly influencing perceptions and experiences of disability." Oliver developed many of Finkelstein's arguments in *Social Work with Disabled People* (1983) and his seminal work, *The Politics of Disablement* (1990). These books had a profound impact and clearly established the credentials of the social model in the international arena.

Oliver (1990: 82) argues that disability is a social creation, rather than a social construction. He distinguishes these views in the following way:

> The social constructionist view sees the problem as being located within the minds of able-bodied people, whether as individually (prejudice) or collectively, through the manifestation of hostile social attitudes and the enactment of social policies based upon a tragic view of disability. The social creationist view, however, sees the problem as located within the institutionalised practices of society.

Oliver suggests that the advantage of seeing disability as a social creation is that such an approach is not idealistic; it recognizes the fundamental importance of material forces and institutionalized structures in the creation of disability. This view identifies areas such as access improvements and anti-discrimination legislation as priority areas for social intervention (Shakespeare, 1995: 24). The social model therefore seeks to provide a structural analysis of the position of disabled people as an oppressed minority (Shakespeare and Watson, 1995).

Mark Priestley (1999) has contrasted the sorts of policy responses which stem from an individual medical model with those of a social model. Priestley shows how a focus on disability, as opposed to impairment, shifts the debates away from medical agendas to a focus on citizenship rights. Rather than emphasizing medicalized responses, and conceptualizing the issue as an individual problem, the social model identifies disability as a social problem associated with issues of rights, discrimination and the need for social change. Preistley suggests that when the problem is defined as "otherness," the likely response is segregation, but when the problem is defined as one as civil rights (as in the social model of disability) the solution is more likely to be found in civil rights legislation, political struggle and education.

While a focus on impairment can imply an intricate examination of the bodies of impaired people, a focus on disability implies that more attention is paid to society's response to human variation. Such a critical reappraisal of social and cultural responses to impairment challenges the medicalization of disability. In this context, it is suggested that the issues concerning disability are not simply a health matter or a minority concern but in fact relate to major social and political issues such as social justice, citizenship rights, perceptions of normality, social inclusion and exclusion, the organization of work, the economics of welfare, and the importance of interdependence and difference (Barnes, Mercer and Shakespeare, 1999: 213). In developing such an understanding of disability, it must be acknowledged that different groups of people have different experiences of disability. This is the theme of the next section of this chapter.

VARIABLES AFFECTING DISABILITY

Given that disability is a social experience, it can be affected by a range of other social variables, such as a person's economic position, gender, ethnicity, age, sexuality, and a range of other factors. Christie and Mensah-Coker (1999:25) make an important comment in this regard:

> Social exclusion is also not a simple category; it is a complex process of denial or loss of opportunities and social connections. Not all disabled

> people suffer the same degree or type of exclusion, and many experiences of exclusion are shared with others who are not disabled. This means that measures for greater inclusion of disabled people could assist other excluded people or groups.

The disability movement, as Shapiro (1993: 11) has commented, is a "mosaic movement" because of its diversity, with a myriad of experiences of gender, class, race and ethnicity, age, sexual orientation, geopolitical location, and impairment.

Disability and impairment identities are multi-faceted: they are always laced with ethnicity, gender, sexuality, age, and so on. It is the (difficult) job of disability studies to try to make some sense of those life experiences without minimizing the importance of any salient factor, and to draw out the importance of both social and biological factors at the same time. People with the exactly the same impairment can interpret that experience very differently; and one is not necessarily better than any other. Likewise, people with similar experiences of disability may make sense of those experiences in fundamentally different ways. Disability and impairment make up a big part of some people's identities and a small part of others. For some, it is important to understand disability and impairment within contexts and narratives that connect these experiences to the rest of their lives; for others, it is important that they not be (we see this particularly in the radical individualist strain of some disabled people). It is important that ethnicity, gender and so on not be regarded as "add ons" to a disability or impairment identity. Disability is always gendered; it is always racialized, it is always sexualized, and so on. These are complex and connected phenomenon. Identity is always developed across a multiplicity of discourses and diverse life experiences. In postcolonial writing, this idea has been operationalized through the concept of "intersectionality"—which Smith (1998) defines as a strategy for "reading simultaneity" within the intersections of identities such as race, gender, class and sexuality. Smith does not recognize disability as another factor in this power dynamic, but disability theorists would certainly argue that without a consideration of disability, any reading of intersectionality is incomplete at best, and at worst, theoretically flawed. The following section of this chapter will discuss how disability studies has recognized the intersectionality of gender, ethnicity, sexuality, age, class, space and place, and diverse impairments.

Gender

Over the last thirty years, disabled women and feminist scholars have consistently emphasised the fundamental importance of gender in the experience of disability. Such an emphasis can be found in the work of Boylan

(1991), Campling (1979), Fawcett (2000), Fine and Asch (1988), Lonsdale (1990), Morris (1992, 1991), Thomas (1999), Wendell (1996) and others. Morris (1991) argues that the political agenda of the disability movement has tended to ignore the specific concerns of disabled women with regard to gendered family and domestic roles. Meekosha and Dowse (1997) add that disabled women are often placed in an ambiguous position relative to the public and private sphere; somewhere between the public and the private, and yet framed as a 'burden' in both spheres. Gender, disability and the denial of citizenship rights, are most evident in the areas of sexuality, reproductive and marriage rights. Garland-Thomson (2003) uses the postcolonial concepts of hybridity and exoticism to explore the position of disabled women from minority cultures. Examining the case of Julia Pastrana, a disabled woman who was paraded as a freak exhibit for in the mid-Nineteenth century, Garland-Thomson shows that she was positioned as a hybrid—between human and animal, civilized and primative, normal and pathological. Interestingly, Pastrana was also seen as a gender violator. This connection between gender violation and disability is one of the most interesting and unexplored areas within disability studies because it calls for a fundamental rethinking of the connections between disability and gender (see Fausto-Sterling; Kessler, 2002).

Ethnicity

There is a smaller body of literature on how ethnicity and multiple oppression (in the form of racism, sexism and disability) structures and mediates the experience of social exclusion, for instance the work of Ahmad (2000), Begum (1992), Bignall and Butt (2000), Taylor (1999), and Vernon (1996, 1998, 1999). One study by Ahmad, Darr and Jones (2000) suggests that cultural diversity within the Deaf community is often ignored, so experiences of racist marginalization are rarely acknowledged. It suggests that self-organization by ethnic Deaf people involves negotiating an identity which includes Deafness as well as ethnicity and religion, so professionals have a responsibility to assist Deaf children become aware of their ethnic and religious backgrounds as well as their Deafness. Cross-cultural studies of disability, such as those by Abu-Habib (1997), Jenkins (1998), and Stone (1999) also have something to contribute in this regard, demonstrating the diverse ways in which cultures respond to impairment and construct disability. Another perspective on the issue of "race" and disability can be gained by critically assessing eugenic ideology—a task which Mitchell and Snyder (2003) have shown is a very fruitful field for disability studies.

Sexuality

Neither disability activists nor academics have tended to prioritize the experience of sexuality and love in the study of disability (Shakespeare, Gillespie-Sells and Davies, 1996). However, a small group of writers, including Abello and Parkinson (2000), Appleby (1994), Clare (1999), Shakespeare, Gillespie-Sells and Davies (1996), and Tremain (2000) have examined the implications of diverse sexual choices for the experience of disability. Abello and Parkinson (2000) stress that Gay, Lesbian, Bisexual and Transgender (GLBT) disabled people are often left in the margins both of the disability movement and the GLBT movement. O'Toole (1996) identifies three major problems which lesbians face in dealing with the health care system: no effort is made to document the experiences of disabled lesbians; negative experiences with the health care system are common for disabled lesbians; and when lesbians "come out" to health professionals, they frequently experience adverse treatment.

Age

Age is another factor that can greatly influence responses to impairment. The impact of age and disability has been explored in Walker and Walker's (1998) work on older people with learning difficulties, in Laura Middleton's (1996, 1999) work on the social exclusion of disabled children, in Woodcroft-Lee's (1999) examination of the employment experiences of older disabled workers and in the work on ageing with a disability by Bowe (1990) and Oliver and Zarb (1993). In their study of children and disability, Baker and Donelly (2001) point to four important dimensions of disability which are often common for children. They argue that disabled children generally: have few disabled friends; socialize with peers who are not disabled; are less popular and more often abused than non-disabled children; and have more unstable, conflictual and uncooperative relationships. Baker and Donelly therefore argue that increased attention needs to be placed on the environments in which disabled children grow up—changing family and school responses to disability. Mark Priestley's (2003) work on disability and the life course has made a valuable contribution in this regard, highlighting intersections between disabling practices and aging, parting at the early and later stages of life.

Class

Although medical sociology has played a great deal of attention to the influence of class on health and illness (for instance, Graham, 2000), the intersection of class with the social experience of disability (as opposed to illness) is rarely explored. There are, of course, a few notable exceptions, such as the work of Preece, 1996 and to a lesser extent Drake, 1999. Another important exception is the work of Wilkinson (2003), who suggests that over 37 per cent of low income families in Canada have a child with a disability—but her argument is somewhat unconvincing, since she did not specify the definition of "disability" which she was using. There have also been some interesting individual explorations of the connections between disability and poverty, such as *Deaf Peddler* by Dennis Buck (2000)—but these remain largely anecdotal and are generally poorly theorized.

Space and Place

Geographers such as Butler and Parr (1999), Gleeson (1999), Hall (2000), and Imrie (1996) have also made important connections between space, place and disability. Gleeson (1999: 1) makes the connection quite clearly:

> . . . social and spatial processes can be used to *disable* rather than *enable* people with physical impairments (emphasis in original).

In this context, Gething (1997) suggests that there are a range of issues associated with the Australian rural/urban divide which impact upon the experience of disability, including transport, distance, isolation and problems accessing appropriate services, support and information.

Nature of the Impairment

The nature of the impairment is also a major factor in the extent to which the person identifies as having a disability (Abberley, 1989). People with certain impairments, especially mental health survivors and Deaf people, commonly deny that they are disabled. Sayce (1989) suggests that some of the common reasons given for differentiating the mental health user/survivor movement and the disability movement include: the fact that mental distress is not permanent and people can recover from it; the fact that the disability movement has not taken on difficult issues associated with mental health, such as compulsory treatment; and the belief that there are significant differences in the culture and history of each movement. Similarly, Beresford and Wallcraft (1997: 68) point out:

> Some survivors do not see themselves as disabled because they associate disability with the medicalisation of their distress. There are also fears and anxieties among survivors and disabled people about being associated with the negatives linked with the other group.

Likewise, many Deaf people deny that they are disabled and deny that they belong to the disabled people's movement. For instance, Lane (1995) argues that the Deafness is a linguistic minority which has a distinct culture. To label Deaf people as disabled is inaccurate and oppressive, Lane argues. Townshend (1994: 252) also argues that Deafness is a distinct culture and that Deaf people have their own community—the Deaf community. In a similar vein, Doe (1999: 6) comments

> The *D*eaf social identity is not hearing loss but a socially constructed status which is usually, but not always, based on identifying as not being able to hear, is formed partly by exclusion (from the hearing world) and partly by the formation of a community and a world around a different centre—its own centre . . . Capital D *D*eafness does not represent a disability or impairment but a positive relationship with others who share language and cultural values (emphasis in original).

Of course, as Corker (1996: 50) has argued, the experiences of Deaf people are not uniform, but are affected by a range of social factors including the early language environment, family and community support and the nature of professional interactions.

French (1994c) also expanded on the complex relationship between impairment and disability in an article entitled "Dimensions of Disability and Impairment." She identified four factors which seemed to strongly influence the experience of disability: the age at which a person acquires an impairment, the visibility of the impairment, the degree to which others comprehend the disability, and the influence of illness. Similarly, factors such as the certainty of the diagnosis, the gender and social class of the individual and the "acceptability" of the impairment were also identified as important issues which can influence the experience of disability. French (1994d) also opened up a whole new area for investigation when she focused on the social construction of the "disabled role" and its personal effects on disabled individuals. She identified a range of complex identity issues which disabled people confront and negotiate in their daily lives, issues revolving around the construction and contestation of normality, independence, acceptance and adjustment, internalized oppression and denial. It should be apparent from these discussions that disability is a complex phenomena, which is enmeshed in both the material environment and in cultural practices (Corker and French, 1999: 3). The next section of this chapter considers the complex effects of disability for people with a brain injury.

DISABILITY AND BRAIN INJURY

Many reports have been produced over the last twenty years which demonstrate the extreme disadvantage and significant social barriers experienced by people with ABI. I will summarize some of those reports here, in order to document the disabling barriers experienced by many survivors. A common theme of these reports is that survivors of an ABI have never had their rights acknowledged and their needs met.

Health Department Victoria, Community Services Victoria and the Transport Accident Commission (1991) conducted extensive research into the needs of Victorians with a brain injury, and identified the following needs:

- problems with diagnosis and inadequate staff training in acute care;
- barriers to rehabilitation, including lack of services and exclusionary eligibility criteria;
- insufficient community living options and shortages of appropriate respite care;
- financial problems, particularly for people without compensable injuries;
- the need for vocational and educational assistance;
- the need for support in dealing with challenging behavior, including public education around brain injury;
- lack of support for careers;
- lack of services and transport for people in country areas; and
- specific problems experienced by people from Non-English Speaking Backgrounds, including language barriers.

Similar findings have been reported throughout Australia. Dyke and Hailstone (1989: 92), conducted consultations with disabled people and their families throughout Queensland and concluded that people with a brain injury were severely disadvantaged:

> As a disability grouping, people with a head injury would have to be considered the most disadvantaged of all. Consultations have consistently highlighted how services to people with a head injury are either inappropriate or non-existent.

Elizabeth Kendall (1991) also wrote *A Review of Service Provision in Queensland* which concluded that existing services were not meeting the needs of people with a brain injury. Queensland has the highest rates of brain injury in Australia, but the report concluded that existing services were insufficient, inappropriate and lacking knowledge about brain injury. Also, services were often unavailable to people with a brain injury. Kendall identified deficiencies in services from the time people were admitted to hospital (and often placed in a "Geriatric" unit), to rehabilitation (where large numbers of people were ineligible for the services offered by the Commonwealth Rehabilitation Service), to post-rehabilitation services (for instance, many young people were in inappropriate accommodation in nursing homes) and recreation services (such as the inappropriate placement of young brain injury survivors in day respite services designed for frail elderly people). The lack of adequate transport options was another barrier commonly experienced by brain injury survivors (Kendall, 1991). A review of service provision for people with a brain injury in the rural area of Bundaberg was also undertaken by Leanne Whicker (1993). This review commented on the social isolation and serious accommodation problems which people with a brain injury experienced, as well as the lack of support for families of someone with an ABI.

Around the same time, the Head Injury Council of Australia (1993) published *Human Rights and Brain Injury: What are the Issues?* This book contained an article by Brian Burdekin, who was then the Commissioner of the Human Rights and Equal Opportunities Commission. Burdekin (1993: 22) said that "head injured people, in particular those at risk of mental illness, are among the most disadvantaged in terms of the resources they don't have and to which they don't get access." He also stated that there is a high correlation between psychiatric disability and head injury and made the following comments about people who have such dual impairments:

> In my understanding as a lawyer, somebody who has had a head injury and then develops a psychiatric disability has a dual disability. In every state that I have heard evidence in so far—(that's five out of the six)—there are virtually no resources for people with dual or multiple disabilities. When I ask bureaucrats and governments why this is so, I am left with the conclusion that it is because this group is among the most marginalised and powerless in terms of advocating on their own behalf. They don't fit into any category. The people who deal with intellectual disability really don't see that they cover the field and the people who deal with psychiatric disability say there's not a complete correlation, as there ISN'T and that's the point. There is no complete correlation anywhere. . . . These people, who obviously need help (perhaps more than other groups with a specific disability), get nothing.

> There are virtually no services except for services in a couple of major cities, and certainly none that I've come across in regional or rural areas. (Burdekin, 1993: 22)

The lack of appropriate services was again highlighted in a report on *Young People Living in Aged Care Facilities* published by Headway Queensland (1994). The report noted many examples where a person could have been living in the community, if appropriately supported, but such support was unavailable. It also stated that alternatives to nursing home accommodation for people with a brain injury do not exist in Queensland.

The Motor Accidents Authority of NSW (1994) also published a report entitled *Improving Long Term Support for People with Brain Injury* which highlighted a wide range of areas where the needs of people with a brain injury were not being met, including accommodation, leisure/recreational and community access programs, respite, vocational support, transport, crisis management, self-help and self-advocacy, and community education.

Then Executive Director of the Brain Injury Association of NSW, Frida Hilson, stated in 1996 that there were insufficient services, staff lacking a knowledge in dealing with brain injury, inappropriate services, and consistent bias against brain injury survivors by service providers:

> People who have had a brain injury are not considered to be a priority group for service provision by most service providers in the disability field including the largest service provider in NSW, the NSW Department of Community Services which continually redefines its service eligibility criteria in a way that excludes people with ABI from receiving services (Hilson, 1996: 4).

An *ABI State Plan* was developed in Western Australia in 1996 (Day, 1996). This Plan recognized that there were serious shortfalls in the areas of information, accommodation and respite, employment, transport, recreation, and many other areas. It commented:

> There is no fully integrated, coordinated system of services able to meet the needs of people with ABI, or the needs of careers. Additionally, gaps and inadequacies exist in the provision of and access to current services. Some generic services have limited capacity to address the specific needs and issues facing people with ABI. The availability of accommodation options is limited in both number, appropriateness and availability (Day, 1996: ii).

Making Rights Count: Services for People with a Disability published by the Commonwealth Department of Health and Family Services (1996) stated that throughout Australia, people with brain injuries were experiencing significant problems trying to access social and vocational rehabilitation services. Specifically, the report (1996: 141) stated:

- Few services are equipped to offer quality support to people with ABI;
- People with ABI often find it difficult to meet the eligibility criteria of service providers because of the hidden nature of ABI and the fact that support needs may change over time;
- There is little accessible information for people with ABI; and
- Service staff are not sufficiently trained in understanding ABI issues.

In 1997, the same message was repeated in Federal Parliament. A speech by Senator Gibbs (1997) raised the issue of ABI as a matter of public interest. Senator Gibbs reflected on the need for more appropriate services nationally by commenting that "In New South Wales, Victoria, Queensland, Tasmania, Western Australia and the ACT, young people with ABI are inappropriately accommodated in acute hospital beds, aged care nursing homes, aged hostels or the mental health system." In Queensland, Senator Gibbs said that there was only one hospital with a specialized ABI unit. "Unfortunately, though," she said, "it can cater for just 140 cases per year, when there are 2,500 cases per year that need the service it provides."

Melbourne Citymission produced a Report entitled *Study into the Accommodation Needs of Young People Requiring Nursing Home Level of Care* in 1999. This report commented that throughout most of Victoria, nursing homes are the only option for young disabled people who have high support needs. The report also noted that a large percentage of these people have an ABI. Melbourne Citymission (1999: 2) concluded:

> Placement within facilities focused on providing geriatric (sic) care is, by and large, inappropriate for a young person who needs to have an ongoing active life.

Disability Services Queensland, in conjunction with the Acquired Brain Injury Outreach Service and the Brain Injury Association of Queensland, (2000: 2) has recently issued a *Discussion Paper on the Needs of People with Acquired Brain Injury* stating:

> Based on international models and in recognition of the unique constellation of disabling issues confronting a person with ABI, it is common for some specialist services to be available as a resource for the community disability sector. In Queensland few such specialist disability services are available. Some generic community and non-specialist disability services in Qld routinely refuse services to people with ABI and their families . . . People with ABI have had minimal success in gaining access to accommodation options, rehabilitation, skills training, employment opportunities, school and tertiary education and a host of other services which are generally assumed to be available to Australians on a universal basis.

Unmet needs identified in this report include: accommodation support, respite support, coordination of support, community access and recreation, behavioral support, support for families and careers, enhanced skills, collaboration between services, therapy and transitional support, advocacy, employment support and research into ABI.

This brief review demonstrates that over the last twenty years, brain injury survivors have never had appropriate services, support or advocacy. Basic human needs, like getting rehabilitation or finding accommodation, have been fraught with danger for a very vulnerable group of people. However, the problem with relying on government reports to indicate the existence of disabling barriers is that they tend to be very "dry" and lose the emotional connection to people's feelings and lives. In order to avoid this limitation, in Chapter Six I will rely on data presented by members of the group about some of the disabling barriers they have experienced.

Whereas the social model suggests that people with a brain injury should align themselves politically with other disabled people, it is interesting to note that many brain injury organizations have adopted a quite different political position. They have instead chosen to focus on the "survivor" identity. Partly, this has been forced on people with an ABI, because disability groups have refused to accept people with an ABI as "disabled," and have refused to provide services to them (Disability Services Queensland, Acquired Brain Injury Outreach Service, and Brain Injury Association of Queensland, 2000). This political strategy has both disadvantages and advantages—while it means that brain injury survivors may be less likely to position themselves alongside other disabled people, it also creates coalitional opportunities with other groups who identify as "survivors." For instance, coalitional possibilities emerge with psychiatric system "survivors," and those battered women who identify themselves as "survivors."

EFFECTS OF DISABILITY

The effects of disability are felt at a social, cultural, economic and personal level. At a social level, disabled people have often been placed in relatively powerless positions—such as in segregated institutions, in social and economic poverty, and with limited social support. Morris (1991) suggests that such segregated institutions undermine notions of disabled people as equals and instead conjure up images of disabled people as aliens and monsters. She feels that institutionalization imposes powerlessness on disabled people. Also, segregation and inadequate support have negative effects both on disabled and nondisabled individuals. Disabled people have been denied choices and opportunities, and nondisabled people have been denied the chance to learn to appreciate differences and understand the true nature of the human condition (Hahn, 1986).

At a cultural level, disability has commonly been equated with tragedy and a range of negative stereotypes have developed about disabled people. Generally, the social model has emphasized the material aspects of disability more than the cultural elements (Shakespeare, 1994b) and the issue of representation has been under-explored within disability studies. There have been some notable exceptions, however, including the work of Garland-Thomson (1997a), Hevey (1992), Keith (2001), Meekosha (2001), and Shakespeare (1994b).

Keith's (2001) study of the representation of disability in classic fiction for girls argues that whether disabled people are pitied, blamed or punished, they are always constructed as 'abnormal.' There is nothing positive about disability in this form of cultural representation. Keith stresses that disabled people are socialized through these texts to behave submissively—to have patience, to be cheerful and to make the best of things. These are precisely the sorts of messages women have received as a result of patriarchy. Disabled characters in these texts exist simply to teach non-disabled people about acceptance of suffering before they are 'released' from their struggle with impairment and die. Meekosha (2001) also emphasizes the importance of the mobilization of stereotypes in the construction of disability. She emphasizes four distinct aspects of representation: the construction of otherness; the power inequalities which underpin representation; the role of fantasy; and fetishism. All of these factors are important in the experience of disability.

Barnes (1992b) also identified twelve commonly occurring stereotypes around disability in the media, which portray the disabled person as: pitiable and pathetic; an object of violence; sinister and evil; atmosphere or curio; super cripple; an object of ridicule; their own worst enemy; a burden;

sexually abnormal; incapable of participating fully in community life; and as "normal." Such cultural stereotypes reinforce negative attitudes towards disabled people and are typically soaked in paternalism (Charlton, 1998: 3).

Disability is always felt at a personal level. Many disabled people have commented on how sad they are to be denied opportunities that so many other people take for granted, like attending regular schools, workplaces and leisure activities. In discussing his own experiences of vision impairment, Barnes (1996a) discusses three common personal effects of disability: minimization (limiting other people's knowledge of your impairment so that you appear 'normal'), overcompensation (trying to develop socially valued attributes to deflect attention from your impairment) and openness (being honest and open about the extent of your impairment and making your impairment-related needs known as they arise). The tactic of minimization seems very common. Morris (1991) suggests that many disabled people try to pass as non-disabled because they receive very clear messages about the negative connotations of disability. With little access to alternative viewpoints about the value of our bodies, our selves and our lives, non-disabled people's perceptions often dominate the self-image of disabled people. Concealment of disability is often reinforced by stigma, discrimination, segregation and inequality.

RESPONDING TO DISABILITY

A range of social, political and cultural responses to disability are discussed in the literature. One of the most popular means of responding to disability is through the provision of anti-discrimination and civil rights legislation. The fight for civil rights has been at the forefront of the disability movement, alongside independent living and the social model (Oliver, 1999: 17). Such an emphasis on civil rights has been very influential in American writing on disability (for instance, Fleischer and Zames, 2001; Shapiro, 1993). The theme of citizenship rights for disabled people was also quite central to Diane Driedger's (1989) study of Disabled People's International, entitled *The Last Civil Rights Movement*. This work positioned the disability movement alongside other civil rights struggles, including the black movement and the women's movement. It emphasized inclusion, equality and participation, recording the ways in which disabled people internationally were mobilizing in order to enhance and protect their citizenship rights. Driedger also highlighted the differences between traditional organizations for disabled people (such as charities) and those organized by disabled people themselves.

Self-organization was presented as a direct challenge to the stereotypes of disabled people as helpless, tragic, passive and dependent.

This response to disability is quite different from the approach known as "Social Role Valorization" or "Normalization" as developed in the work of Wolfensberger (1972, 1975, 1983, 1987). Normalization involves an attempt to structure service delivery and to organize the lives of disabled people in a certain way to ensure that they occupy "socially valued" roles. Wolfensberger and Thomas (1983: 234) argue that human services should support disabled people in participating "in valued activities, in valued settings with valued citizens." This means that the service should blend into its community setting. It should also be located away from devalued groups and should engage in activities which enhance the social image of its clients. Within some sections of the disability movement, significant objections exist in relation to the philosophy and practice of normalization. The major concerns which have expressed about this approach revolve around the conservative nature of normalization. It is an approach which tries to change disabled people rather than changing the practices of a disabling society. Also, it assumes that the norms of the dominant group in society are unproblematic—that disabled people need to adopt "socially valued" identities rather than building their own positive social identity as disabled people. In this regard, normalization seems quite hostile to diversity and difference (Szivos, 1992).

Mackelprang and Salsgiver (1999) argue that these debates have major practice implications for workers in the human services. They develop six principles for human service delivery in responding to disability:

1. Workers must assume that disabled people are capable, or potentially capable.
2. Any assumption that the person needs to be "fixed" or changed needs to be rejected totally.
3. As disability is a social construct, political interventions are necessary.
4. Support must be provided to people who express a culture or identity of disability.
5. Workers need to recognize that disabled people may have experienced oppression, but there is still joy to be found in the experience of disability.
6. Disabled people must be in control of their own lives.

The fifth principle developed by Mackelprang and Salsgiver (1999) reflects an understanding of disability which is similar in some respects to the "affirmation model of disability" developed by Swain and French

(2000). In this model, the focus is on the positive social identities (both individually and collectively) which develop from disability pride. There are parallels the identity politics of other social movements such as the "black is beautiful" and "gay is good" slogans. However, whether the "affirmative" model implies that disabled people should engage in flaunting is unclear.

It seems to me that there is a need for disability activists not simply to mimic other social movements but to think through the implications of drawing upon affirmative slogans such as "black is beautiful" or "gay is good." For instance, I think it would be useful for disability studies to explore the dynamics of Negritude before uncritically citing that discourse. Negritude, a term first coined by the Martinician poet Aimé Césaire, was a particular approach to African diasporic identity in which African heritage was revalorized rather than soaked in shame. It was regarded as a strategic step in the development of black consciousness—but has been critiqued as "a problematic response to Western creations of alterity" (Thieme, 2003: 183) because it involves an essentialist view of black people. The danger of essentialist approaches to identity is that they become a part of the process of exoticizing and othering groups who are different (Lionnet, 1995). The lesson from this debate, argues Roger Toumson (quoted in Lionnet, 1995: 34) is that we need to challenge "the discourse of absolute otherness." Disability studies would be foolish to ignore this debate and reproduce the mistakes of the past.

EXAMINING THE UNDERLYING THEORY—THE SOCIAL MODEL

The social model, which underpins most discussions on disability in the literature (particularly British literature), begins with a conceptual distinction between impairment and disability. As was noted in Chapter One, separating impairment from disability and sex from gender is a political and theoretical tool in understanding and opposing social inequality. This stance has taken both gender and disability out of the 'private' realm and identified it as a 'public' issue, revolving around citizenship rights. Meekosha (1999: 1) comments:

> We all have basic rights whatever the status the wider society seeks to impose on us.

Many authors use the social model to challenge the medicalization of disability and to criticize medical practice. The medical tendency to label every difference within the mind or body of a disabled person has been particularly criticized. Brisenden (1998: 21) highlights the way disabled people are often put into certain pigeon holes according to their medical diagnosis: people with cerebral palsy, for instance, may be labeled "spastic" and treated as if they were "a raving, dribbling idiot" as a consequence of the indignity associated with the label. The person inside the label is completely ignored in this labeling process. His or her uniqueness, rights and individuality are robbed once a disabling label is applied. As Brisenden (1998: 21) states:

> These words that lump us together- "the disabled," "spina bifida," "tetraplegic," "muscular dystrophy"—are nothing more than terminological rubbish bins into which all the important things about us as people get thrown away.

One problem with the medical model of disability is that because of its obsession with labeling, it fails to recognize the strengths and uniqueness of an individual with a disability. It is often suggested that the social model promotes a more balanced view of the individual. Many authors using the social model have denied that disability should be regarded as a loss and have tried to stimulate disability pride. For instance, Hahn (1988) argues that the experience of disability is increasingly being defined as a unique opportunity to reflect on the meaning and purpose of life, as well as a chance to become involved in a struggle for human rights. By focusing on accepting human differences, such a struggle can be both empowering and enriching. The social model therefore supports the strategies which disabled people have developed to promote their experiences in a positive way:

> . . . the personal and public affirmation of disabled identities and the demands that disabled people be accepted by and integrated into society as they are; that is, as disabled people (Oliver and Zarb, 1989: 225).

CRITICISMS OF THE SOCIAL MODEL

While the social model has great value as a critique of medical practice and as a framework for the assertion of the rights of disabled people, it also has a number of practical and theoretical weaknesses. For instance, the impairment/disability divide seems to imply that impairment has nothing to do with disability (Corker, 1999). An extreme example of this argument can be found in a review of Rob Imrie's book, *Disability And The City,* by the

British academic Paul Anthony Darke (1998). Darke (1998: 223) believes that "the body and the individual with an impairment have nothing to do with disablement as disability is a social construct that is tied to all things that are extrinsic to the impaired body." Darke dismisses both Imrie's and Jenny Morris' work as "undermining disabled people's advancement" because they discuss the impact of impairment on disabled people. Indeed, Darke's extreme position is that "there are 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" (1998: 224). Corker (1999: 633) criticizes this dualistic approach:

> In their everyday 'talk,' disabled people often allude to a complex existence that occupies the space between health and illness, disability and 'normality,' impairment and empowerment and nature and culture, to give a few examples. However, disability theory continues to dichotomise these things in a way that does not permit exploration of the space between.

In a strict social model approach, disability is not an embodied experience. Priestley (1999: 49) makes this quite clear. He argues that disability has nothing to do with embodiment:

> . . . the embodiment of disability depoliticises discrimination and obscures the lack of state intervention for its amelioration.

Such a position can be contrasted with the work of disabled writers who have explicitly tried to include discussion of embodiment in their work. For instance, the late Irving Kenneth Zola advocated that a focus on embodied experiences was precisely what was needed. Before his death, Zola (1991) suggested that it was necessary to break the "structured silence of personal bodily experience." Drawing on parallels with feminism, Zola (1991: 2) argued that it was essential to recognize the effects which living with an impairment has upon a person's identity:

> I want at the very least to bring these personal bodily experiences closer to my centre- not to claim that they constitute all of who I am, but that they are a central part of my identity; not that they explain all I have accomplished, but that they are essential to understanding what I have done.

Likewise, Toombs (1994) argues that the experience of impairment and disability frequently have significant embodied consequences: they may involve a transformation of body identity, altering self-presentation and affecting the social self.

Unfortunately, as its influence has grown, the social model has become something of a political orthodoxy which is rigidly and inflexibly applied by certain sections of the movement. This orthodoxy has meant that some scholars who want to discuss issues of embodiment have actually been denigrated and ridiculed by (mostly male) disability studies academics, on the grounds that their approach undermines the social model of disability. This position stands in stark contrast to the growth of a significant amount of feminist literature on embodiment, including contributions from Braidotti (1994), Bray and Colebrook (1998), Gatens (1996), Grosz (1994), Haraway (1991), Irigaray (1985) and Parkins (2000). Chapter Seven will seek to explore some of the areas which have been silenced in the social model (such as embodiment). In Chapter Seven, these areas are defined as "differend" perspectives—a term coined by the French theorist Jean-Francois Lyotard (1988) to describe conflicts that involve fundamental disagreements of interpretation, where one position is often silenced (or at a "loss for words") if the other perspective becomes dominant.

Despite the absence of a detailed examination of embodiment within the social model of disability, a wealth of sociological literature on the body has been written in recent years, including work by Frank (1990, 1991), Grosz (1994), Shilling, (1993, 1999), Turner (2000), Williams and Bendelow (1998) and others. These works have examined the complex and subtle ways in which the body is enmeshed in social relations. Flax (1993: 98) states that "embodiment," in this sense, "is simultaneously somatic, psychic, and discursive." Similarly, Frank (1990: 49) suggests that institutions, discourses and corporeality all play a central role in embodiment, providing frameworks in which we understand, represent and experience our bodies in a social and physical sense. Turner (2000) argues that a sophisticated understanding of embodiment must involve systematically examining the body in terms of its corporeality, sensibility and objectivity, as well as developing an embodied sense of social agency. Shilling (1999) points to an important reason why embodiment has not gained more significance in the literature. He argues that it is quite common for structuralist perspectives to have a relatively disembodied conception of agency.

The social model adopts a structuralist perspective which inherently runs a risk of underestimating individual human agency. The main problem with such an approach is that it portrays disabled people as powerless in the face of overwhelming structural barriers. This is not a satisfactory theoretical approach to this issue, because it overestimates the strength of disabling hegemony, and seems to imply a linear development of disabling barriers. A more rigorous theoretical approach must acknowledge the existence of human agency alongside, and in spite of, disabling barriers. Such an endeavour probably needs to begin at the local level, where individuals and groups of disabled people form together to respond to oppression and inequality. In Chapter Seven an attempt will be made to acknowledge such agency.

The moral dimensions of social conflicts identified by Honneth (1995) are another important dimension of the struggle for disability rights which are frequently neglected in the social model. Honneth (1995: 136) stresses the importance of "intersubjective recognition" and argues that love, rights and solidarity are central forms of recognition and respect. Although some new work in the disability area is beginning to engage with this moral dimension of respect and recognition (such as Schofield, 2001 and Shakespeare, 2000), it is fair to suggest that disability studies needs to pay more attention to this area, because there are significant moral issues around social inclusion and exclusion. To ignore these issues is to fail to grapple fully with the experience of disability. A major element of the struggle for a better world for disabled people must be a struggle for rights, recognition, respect, solidarity and love. A lack of love, as Honneth (1995) has suggested, is a major form of disrespect, which many disabled people, including the participants in this study, experience. This theme will be reexamined in Chapter Six, where participants discuss how a lack of friendships, solidarity, love and support has affected them.

Shakespeare and Watson (1995) have warned that a narrow focus on embodiment may lead to a failure to examine the social and power dimensions of an experience. They argue that medical sociology frequently ignores the social dimensions of disability oppression, choosing instead to treat it mainly as an individual medical experience. Shakespeare and Watson (1995: 11) argue that medical sociologists tend to describe disabled people's experiences simply in terms of biological frailty rather than socialized experiences, and call for an "ethnography of physicality" which problematizes the lived body and examines the lived experiences of embodiment. However, in calling for an "ethnography of physicality," Shakespeare and Watson seem to be assuming impairment and disability are physical experiences. This assumption is questioned by many of the participants in this study, who would position them as also being cognitive experiences. Nevertheless, Shakespeare and Watson's argument is similar to that made by Honkasalo (1998), who suggests that any study of embodiment requires, rather than excludes, a critical analysis of power, structure and historicity. In this context, it is surprising then that the social model has not taken the sociological concept of embodiment more seriously.

Garland-Thomson (1997b) has pointed to four of the issues which could comprise the key elements of a study of embodiment within disability studies:

1. Cultural representations of the body.
2. Ideological discourses underpinning those representations.
3. The effects of those representations (political, social, material).
4. The relationships between representations, biology and the lived body.

The reason a focus on embodiment, and in particular impairment, is necessary has been outlined by Jenny Morris (1991) in her very influential book *Pride Against Prejudice*. Morris argues that the medical model is a very important element of the powerlessness experienced by disabled people. However, in trying to challenge the dominance of the medical model, Morris believes that some disabled people have denied the personal elements of disability. She stresses that disability is linked with frailty, pain, illness and old age. She argues that disabled people must speak about all the elements of their experiences, including difficult topics of pain and impairment, otherwise they will be isolated and feel a sense of personal responsibility or blame for their experiences. Likewise, Sally French (1993) has argued for disability scholars to broaden their dialogue in order to include a discussion of the complexities of impairment, disability and "the middle ground" which involves neither impairment nor disability, but is connected to both of them. French stresses that there are many important aspects of her life with a vision impairment which cannot be addressed through the social model's emphasis on disabling barriers. French (1993: 17–18) states:

> . . . various profound social problems that I encountered as a visually impaired person, which impinge upon my life far more than indecipherable notices or the lack of beeper crossings, are more difficult to regard as entirely socially produced or amenable to social action. Such problems include my inability to recognise people, being nearly blinded when the sun comes out, and not being able to read non-verbal cues or emit them correctly . . . the difficulty I have described is not entirely due to my impairment, for it involves other people's responses, but neither is it easily modified by social or environmental manipulation; it occupies a middle ground.

French acknowledges in her article that disability activists generally disparage such comments because they break down the “united front” of disabled people trying to convince skeptical audiences that the problems lie in a disabling society, rather than in disabled people’s bodies. Indeed, there has been considerable reluctance on the part of many (particularly male) disability activists to admit the complexities and frailties associated with impairment as a sentient experience. Instead, the response of these people has been to re-emphasize the importance of social barriers and to suggest that discussions of impairment are politically dangerous. For instance, Finkelstein (1996: 34) dismissed such discussions as a “discredited and sterile approach” which involved “contemplative and abstract concerns about subjective experiences.” Barnes (1998: 77) also argued that discussions of impairment have:

> served only to endorse negative cultural stereotypes of disabled people and, in so doing, detract attention away from the material and cultural forces which compound disabled people’s disadvantage.

Elsewhere, Barnes (1996b: 27) argued that the criticisms of the social model amount to “mythmaking” around a number of “misconceived and damaging assertions” by people “who are driven by either ignorance or their own personal agenda” and who “seem intent on undermining what has already been achieved by generating and perpetuating a number of misguided myths.”

Such comments have understandably angered disabled feminists. Indeed, Corker (1999: 629) has gone so far as to label this tendency “malestream disability theory” which involves:

> self-imposed limitations of censorship, silencing, subordination and negative evaluation, which has resulted in the policing of disabled people’s experience.

Crow (1996) has also suggested that within the disability movement, it is often “safer” not to mention impairment. She expressed her “trepidation” at discussing the imposed silence around impairment, but suggested that “this silence prevents us from dealing effectively with the difficult aspects of impairment” (Crow, 1996: 209). The unease which has developed over such censorship has been raised by Linton (2000: 700) who argues that discussions of impairment and phenomenological approaches to the sentient body are being stifled by an “ideologically hostile environment” of social model orthodoxy.

Shakespeare (2000) and Thomas (1999) have made some interesting comments in this regard. Thomas (1999: 74) has suggested that the public/private divide which underlies the work of many male social model theorists is:

> singularly unhelpful to those who want to further develop a theoretical understanding of disability which is concerned with both the macro and the micro, with both structure and individual agency, with the socio-economic and the intimate.

Shakespeare (2000) also argues that the reason for the disability movement's failure to address areas such as impairment, and indeed sexuality, is that there has been a tacit acceptance of the public/private divide by the disability movement. He attributes this limitation to European, masculinist trade union and socialist influences which prioritize economic and material issues over domestic ones.

Another distinct problem within the social model is that the whole concept of a disabled identity is considered unproblematic in much of the literature: a person is disabled if they identify as disabled. Such a position is explicitly stated by Gabel (1999) and Linton (1998a). Marks (1999) comments that the process of identifying as disabled is far more complex than this simplistic formula suggests. She believes that self-hood and identity are fluid, contingent and variable. Furthermore, the social model also does not respond well to people who have chronic illnesses or impairments but deny that they are disabled. Stone and Priestley (1996) suggest there can be serious conflicts when the social model is not part of participant's own understanding of the experience. Marks (1999: 88) suggests from a social model perspective, these people are simply labeled as having "false consciousness." Obviously, this is a theoretically and politically unsatisfactory solution to this problem.

Disability studies is therefore at something of a political and theoretical impasse. Many disability activists are strongly committed to the social model in both theory and practice. It has played an important role in their lives and identities, and continues to be an important element of the struggle for civil rights. However, the binary impairment/disability divide which underpins the social model is increasingly being exposed as flawed and theoretically inadequate. It also fails to acknowledge the complexities of people's lived experiences and has become something of a political orthodoxy which prevents open discussion of impairment.

It would be fair to suggest that the social model of disability is a thoroughly modernist approach, built on a binary disabled/non-disabled distinction and an impairment/disability divide. However, these distinctions are deeply problematic and it may be valuable to consider what a postmodern approach to the experiences of disability and impairment might look like. My approach is like that of Nicholson and Seidman (1999) who argue for a "social postmodernism" which integrates both the micro-analysis of the new social movements and a broader institutional and cultural framework. Corker and French (1999: 2) suggest that the impairment/disability dualism which lies at the heart of the social model has been enmeshed in power/knowledge networks which silence impairment and valorize disability. Likewise, the disabled/non-disabled divide should be associated with particular relations of power and a particular social /cultural framework. As Davis (1995: xv) comments:

> People with disabilities, rightly, have seized on the term in an attempt to control its usage; but even with that empowering move, it is necessary to remember that the term still serves at least two masters.

Disability is a loaded term. It is difficult to speak of a unified body of "disabled people" because some people are understandably reluctant to identify with the most stigmatized parts of their identities. In his wonderful analysis of the development of the American disability movement, Shapiro (1993: 7) comments on the reluctance of so many people with impairments to identify as disabled:

> . . . even at the lowest estimate, disabled people could be considered the nation's largest minority. Not all disabled people, however, see themselves as part of a minority group. Many even deny that they are disabled, to avoid the taint accompanying that label.

There are many social processes which discourage people from identifying as disabled. Davis (1995) has developed the concept of "hegemonic normalcy," which refers to the continuous social processes comparing, representing, silencing, constructing and deconstructing images of normalcy and the abnormal. Historically, disability has been defined as a form of inferiority, as a deviation from the "normal." In cultural terms, the development of disability identity is inseparable from the construction of difference and "Otherness" (Perry and Whiteside, 2000). The separation and opposition of "disabled" people from "normal" people is one of the major cultural practices which devalues disabled people and their bodies (Butler and Bowlby, 1997). Attribution of inferiority to disabled people silences and invalidates disabled people's experiences. Munford (1994: 7) comments:

> The challenge then is to resist binary divisions that put the person with the disability in the role of the 'other,' to move from the notion of an 'essentialised' disabled person and in doing so acknowledge the multiple subject positions of people with disabilities in order to embrace diversity; and, alongside of this, develop identities wherein commonalities between individuals can contribute to building alliances for bringing about change.

Fawcett (1999) agrees, commenting that it is necessary to develop ways of recognizing that disabled people are both constructed through mechanisms of power and exclusions, but also resist such power structures and find opportunities for action in certain contexts. She goes further however, by suggesting that it is necessary to reject any grand narratives of disability because they fail to fully appreciate diversity, fluidity and difference.

There are parallels within feminism for this debate over identity. Butler's (1990) exploration of the power dynamics underlying gender identities is particularly relevant. Butler argues that feminism has often assumed that there is a pre-existing identity, understood through the category of "women," who have developed feminist discourse, but who also constitute the subject for political representation. A similar argument could be made that social model writers have often assumed there is a pre-existing identity of "disabled people" who are the centre of its emancipatory project. Butler highlights the flaws in this approach by focusing on the way an identity (like gender or disability) is rarely constituted coherently or consistently. It is likely to vary from time to time and from place to place, and is a site of contest because it is always interspersed with racial, class, ethnic, sexual, and regional identities:

> As a result, it becomes impossible to separate out "gender" from the political and cultural intersections in which it is invariably produced and maintained (Butler, 1990: 3).

For Butler, power relations constitute identity, but they also make the singular notion of "identity" a misnomer. It is impossible to uphold a single category of "women" or "disabled people" applying Butler's approach, even if the intent is emancipatory, because such an approach inevitably produces multiple refusals to accept the label. Instead, the political imperative is to form coalitions which acknowledge difference and allow dialogue where people can articulate their distinct positions. Butler's theory of "subjection" has been largely ignored in disability literature; Chapter Seven will explore some areas where it could be applied to experiences of disability.

Likewise, Shildrick's (1997) examination of "leaky bodies," feminist theory and postmodernism highlights the fact that a postmodern perspective is often problematic in the sense that it seems to undermine the very ground on which emancipatory projects are built. It can be constructed as a threat to feminism, and also to disability studies, insofar as it threatens to deconstruct the very identity categories which are central to those disciplines. The very categories of "women," "disabled people" and so on become contested concepts within postmodernism. This does not mean that the concepts are abandoned, however. Shildrick (1997: 2) suggests:

> Where signification is acknowledged as slippery and treacherous, the issue becomes not the creation of new normative standards, but a persistent endeavour to forefront the instability and provisionality of the concepts with which one is dealing.

In terms of highlighting instabilities around identity, disability scholars can learn a great deal from the body of work broadly known as queer theory. Although queer theory is not a singular or systematic concept or methodology, it can be understood as a body of work which sits uncomfortably in relation to the sex/gender divide. It was suggested earlier in the chapter than the sex/gender divide provided an important political and conceptual springboard for the development of the social model, by attempting to separate issues of biology from socialization. However, queer theory has shown the problems such a binary model poses for people who sit uncomfortably outside it, such as transgender people, bisexuals, transsexuals and people who define their gender with sexuality via sexual practices, such as sadomasochists (Spargo, 1999).

Postcolonial and ethnic minority theorists such as Bhabba (1990), Brah (1996), Mac an Ghaill (1999), and Said (1993) have developed positions around race and ethnicity which are quite similar to those articulated by queer theory in terms of their rejection of essentialism and dualisms, as well as in their emphasis on difference and diversity. Postcolonial theory has recognized that categories of identity (such as an "African identity") may have political and rhetorical power, but has also emphasized that such identities are fluid, provisional, contested, and interspersed with other categories of identity (Appiah, 1999). Like early social model theorists, early accounts of racism and ethnicity placed significant emphasis on class as understood through a materialist perspective (Mac an Ghaill, 1999: 25). However, later accounts suggested that racialized social relations, like gendered social relations and disabling social relations, are located at the intersection of different forms of social differentiation, subjectivity and identity formation. There is a need to go beyond binaries (in this case, black/white binaries) and to examine the complexity of changing formations of multiple racisms and new ethnicities. It could be suggested that the lesson for disability studies is that rather than looking for a binary disabled/nondisabled social relation, it is necessary to recognize the multiple, fluid and contradictory social relations which underpin shifting identities and conceptions of citizenship.

One of the problems associated with theorizing disability identity is that disability has historically been assumed to be a "master status." As Asch and Fine (1988: 3) commented in their groundbreaking work on women with disabilities:

> To date almost all research on disabled men and women seems simply to assume the irrelevance of gender, race, ethnicity, sexual orientation, or social class. Having a disability presumably eclipses these dimensions of social experience. Even sensitive students of disability . . . have focussed on disability as a unitary concept and have taken it to be not merely the 'master' status but apparently the exclusive status for disabled people.

The fact that regimes of bodily power are at the centre of struggles over impairment and disability presents opportunities for the building of coalitional politics. Garland-Thomson (1997a) is one of many authors who liken women's struggles around body image to similar struggles of disabled people. As Fawcett (2000: 42–43) has argued, personal experience of disability is not a prerequisite to having a political commitment to overcoming injustice and removing disabling barriers. Fawcett warns that as a political strategy, relying only on those who can claim a personal experience of disability means that non-disabled people may feel excluded from the process and wider coalitions may not emerge. However, by finding common ground, such as a struggle over body image, coalitional possibilities arise.

In terms of identity politics, postmodern approaches substitute the politics of difference for the rhetoric of liberation. Instead of naturalizing or essentializing categories of identity, as the social model does with regard to "disabled people," a postmodern approach seeks to demonstrate the contingent and historically variable meaning of the category of disability. This means that political struggles around "disability" need to be based on the recognition of difference rather than imputed common experiences. Coalitional strategies are essential in this regard. In many respects, the social model has been based on a minority model of political participation.

This is problematic because it is anchored in the assertion of a unique disability identity. A postmodern approach would reject approaches which seek to label identity in binary disabled/non-disabled terms. It would suggest that imposing one disability identity on segments of the community whose own perceptions of their identity is different is to engage in power practices which are disciplining and normative. Postmodern theories may also be useful because they highlight the issue of representation and do not regard language as a direct mirror of reality (Alvesson, 2002). Hence a postmodern approach which regards disability and impairment identities as conflicting and multiple, as well as interspersed with class, gender, race, sexuality, and other identities, provides more space for individuals wanting to position themselves in alternate ways. Nicholson and Seidman (1999) identify the political implications of this Postmodern approach: it involves the deconstruction of identity politics, and the development of coalitions around specific issues, strategies and goals.

Underlying a great deal of social model writing is the assumption that all disabled people share common experiences, particularly experiences of discrimination (Barnes, 1990; Oliver, 1996). However Young (1990) warns of the dangers of a political theory which has a tendency to suppress difference by making assumptions that people have universal and unified experiences. Her position (1990: 10) is that:

> A conception of justice which challenges institutionalised discrimination and oppression should offer a vision of a heterogeneous public that acknowledges and affirms group differences.

Listening to voices of difference within the disability movement is valuable not just because it acknowledges the diversity of experiences but also because it provides a more accurate and realistic description of the richness of lived experience. Implicit in this analysis is the concept of multiple identities. Young (1990: 48) explains this concept in the following way:

> This view of group differentiation as multiple, cross-cutting, fluid, and shifting implies another critique of the model of the autonomous, unified self. In complex, highly differentiated societies like our own, all persons have multiple group identifications. The culture, perspective, and relations of privilege and oppression of these various groups, moreover, may not cohere. Thus individual persons, as constituted partly by their group affinities and relations, cannot be unified, themselves are heterogenous and not necessarily coherent.

Following Fraser (1995), the suggestion is that it is necessary to build coalitions and generate feelings of solidarity which are "not homogenising and repressive."

Cultural theory has grappled with the questions of identity and difference in some detail. According to West (1995: 147):

> Distinctive features of the new cultural politics of difference are: to trash the monolithic and homogenous in the name of diversity, multiplicity and heterogeneity; to reject the abstract, general and universal in the light of the concrete, specific and particular; and to historicize, contextualize and pluralize by highlighting the contingent, provisional variable, tentative, shifting and changing.

The importance accorded to representation of difference is one of the most innovative elements of this new approach to social theory. The positioning of multiple forms of difference at the heart of social theory means that it is essential to recognize plural, fluid and provisional centers of power and not to imply that there is a universal structuration of power (Shildrick, 1997: 83).

Williams (1996) makes the distinction between difference, diversity and division and these concepts can be fruitfully applied to a discussion of disability politics. Difference, for Williams, involves situations where a shared collective experience informs identity and provides the basis for resistance to oppression based on that identity. By diversity, Williams means a shared collective experience (such as a language or nationality). And by division, Williams identifies those situations where dominant groups develop an identity which protects their privilege. Williams suggests that expressions of difference can lead to the adoption of essentialist positions which obscure or deny commonalities with other people. What is needed is a respectful acknowledgement of the multiple identities which people have:

> The fragmentation of politics involves a constant freezing and melting and re-constituting of identity. At the same time, we cannot assume that commonalities (as women or among different groups) exist, nor can we override differences with false consciousness. But it is through the process of knowing, acknowledging and understanding the complex relations of power in which we all are caught and the differences they create that we can, from time to time, reach the commonalities we share (Williams, 1996: 72).

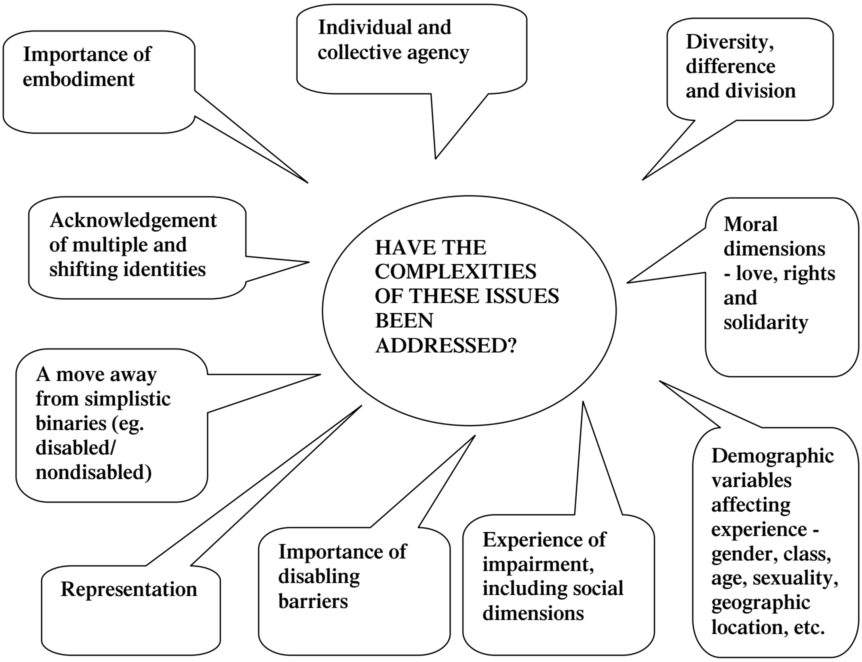

Figure 3.1. Questions for a Study of Disability Address

Figure 3.1 highlights some of the challenges for a study of disability in the context of an interdisciplinary approach. It outlines the need to study impairment, embodiment, identity, agency, as well as the moral dimensions of love, respect and solidarity. It provides a basic introduction to some of the themes which will be addressed throughout this thesis in the study of a small group of brain injury survivors.

CONCLUSION

This chapter has considered the complex nature of disability as a lived, embodied and relational experience. It has highlighted the salience of the social model for many disabled people, particularly in the promotion of civil rights and the vision of a non-disabling society. The terrible effects of discriminatory barriers on disabled people's self-esteem has been highlighted and the need for accessible environments has been emphasized. The use of the social model for the promotion of self-determination by disabled people has also been highlighted. However, the binary impairment/disability divide which forms the basis of the social model has been shown to be problematic. Also, the failure of the social model to engage more constructively with the issues of impairment and embodiment have been highlighted. Furthermore, the social model has been unable to respond well to people with impairments who deny that they are disabled, and has resorted to labeling them as suffering from "false consciousness." So it seems that a theoretical and political impasse has developed in which the social model has become something of a political orthodoxy among disability activists, doggedly defended against all critics. New ways of understanding disability seem necessary, which acknowledge disability as a civil rights issue, but also grapple with the difficult questions of identity, impairment and embodiment. Such new understandings of disability need to acknowledge the range of variables which affect the experience of disability, including gender, race and ethnicity, age, sexuality, the nature of the impairment, and a range of other factors.

Chapter Four

The (Im)Possibilities of "Insider, Emancipatory" Research

INTRODUCTION

After outlining some of the unique challenges of working with brain injury survivors, this chapter will focus on two key elements of the methodological approach used in the study—engaging in "insider" research, and undertaking "emancipatory" disability studies research. While I regard both the idea of being an "insider" and the idea of "emancipation" as problematic concepts, I nevertheless engaged extensively with the literature on this topic, and it undoubtedly shaped my approach to the research question. The data which informs this book comes from a wide range of sources, including reflecting on my personal experience of ABI and my involvement with disability and brain injury organizations, examining narratives written by the research participants, conducting personal interviews during the project, conducting group meetings where we could discuss our experiences, engaging in participant observation, maintaining field notes and a journal, and personally observing other survivors in various contexts. I conducted a small qualitative study in Brisbane, Australia over a three-year period, from 1999 to 2001, recruiting one dozen participants by talking about my research at meetings of the Brain Injury Action Group (BIAG). At the time, this was the only group in Brisbane run by and for brain injury survivors. The people who I asked to participate in this study received their injuries at different periods of time. Some had only been injured in the last few years, while others had received their injuries more than 20 years ago. Each formal interview which I conducted was professionally transcribed.

UNIQUE CHALLENGES OF WORKING WITH BRAIN INJURY SURVIVORS

Some of the challenges which I faced in conducting this research are unique to the specific population of people with a brain injury. These include the ease with which participants could become lost, fatigued or distracted, the problems with communication, the occasional lack of insight into their own behavior, and other behavioral and cognitive challenges related to brain injury. As an "insider," I had some insight into these challenges and I also was aware of some of the strategies I use in my daily life to manage them. I developed research methods which accommodated these requirements. For instance, I know that I am easily distracted, and I know that I often have difficulty negotiating certain types of environments (such as stairs, places with high levels of background noise, certain types of lighting, and places in which it is easy to become lost). I also know that these problems are common for many people with brain injuries. So I thought a great deal about the environments in which interviews were conducted. When possible, I tried to find environments which had very little sensory input—quiet places that were accessible, easily readable, uncluttered, familiar, and with minimal mobility requirements. I knew that people with brain injuries become easily fatigued, and I planned where we would meet in order to minimize the amount of travel we would have to do. I always scheduled regular breaks so that people did not become too tired. The longer the interview went, the longer the breaks were in between our discussions. I even tried to minimize the distance from public transport to the rooms where we would have an interview, to minimize any physical exertion.

Of course, for some people who were in hospitals or nursing homes when I first met them, I had no control over the environment. But even then, we chose quiet places, such as a bedroom or rarely used sections of the courtyard, to meet and talk. I also talked to people about their specific access requirements—such as a room which was accessible to wheelchairs, a requirement for information in alternative formats (such as large print and plain English), and I asked people about their personal assistance requirements. I would sometimes visit people' s houses and travel with them to the interview venue to ensure that they did not get lost on the way.

In terms of the emotional, behavioral and psychiatric challenges which people with a brain injury experience, I tried to think about my impact upon each person's health and wellbeing. I tried to model respectful behavior and read some of the literature from the mental health field about working alongside people who have mental health "problems." I followed some of the suggestions of Perkins and Repper (1996), namely, focusing on the unique circumstances of each individual, being realistic about the rate of progress one can expect, concentrating on building and maintaining effective relationships, and having the humility to accept what I do not know and to listen to the voices of people who do. As Perkins and Repper (1996: 5) comment:

> There is no substitute for talking to each person and exploring their individual world.

Trying to "be there" for people in the good times and the bad was another important element of my work with people with a brain injury. Often people are abandoned, by friends and service providers, once they begin to show signs of difficult behavior. A central element of my research methodology was that research participants continue to have ongoing relationships with me and with each other. The long-term nature of our relationships has impacted significantly on the nature of the data collected in this research, opening up new areas for investigation and enabling some issues to be explored in greater depth. The long-term nature of these relationships also means that we try to have a more positive, empathetic understanding of where each individual is "coming from," their history, their aspirations and their struggles. Having a long-term relationship also means that you are more likely to be trusted when something serious occurs. For instance, someone who is having a psychotic episode can be reassured by a long-term friend that others are not out to get him and this reassurance can be enormously beneficial, preventing the person from harming themselves or others.

Booth and Booth (1997) have written about their research with what they call "inarticulate subjects." I am deeply troubled by this term, as it pathologizes the individuals concerned. Nevertheless, I acknowledge that there are many people with a brain injury who require alternative interviewing strategies in order to participate fully in this research project. Principally, these people required more time, clear explanations, a lack of jargon and a respectful environment where they could tell their own story in their own time. I need to outline the intensity this required, both from me as an interviewer and from them as participants. On average, I saw each participant approximately fifteen times. For the people who Booth and Booth would describe as "inarticulate," the number of visits was much higher. Some days, I would struggle to record one hundred words with these participants. Often we would sit, and I would just be with the person for a few hours. If they didn't feel like talking, I did not pressure them. I often just sat with them, or made small-talk. Sometimes their family members would come and sit with us, sometimes we sat alone. Sometimes we went out to eat, and while we were eating the person would come up with an answer to an earlier question. Sometimes I would write down these responses in my journal; on other occasions I would set up a new formal interview to tape record what the person had to say.

The literature suggests that people with a brain injury are a difficult group of people to interview because: they often provide short answers, with little essential information; they often find it hard to shift the topic of conversation; and they often become side-tracked and overly-focused on the minute details of a story (Snow, Douglas and Ponsford, 1998). Minichiello, Aroni, Timewell and Alexander (1990), in their discussions of the interview process, are particularly useful in developing strategies to elucidate more detailed answers from participants. They suggest that interviewers need to use a range of techniques to gain information: descriptive questioning to start interviews; probing questions to elicit more information; funneling techniques which guide the conversation in a certain direction; and cross-checks to ensure that the interviewer has gained an accurate understanding of the person's message. I tried to practice these listening and interviewing techniques before I interviewed people so that interviews would be effective.

Minichiello et al. (1990) also give a number of useful suggestions about setting the tone of the interview and developing rapport with the participants. They indicate that before interviews are conducted, there should be a discussion with participants of issues such as confidentiality and anonymity, the motives and intentions of the researcher, and who gets the final say on the manuscript. This was a useful starting point and provided the following parameters for the interview process. These were: all interviews would be confidential and anonymous; my intentions as a researcher would be clear; and other research participants would have the final say in what descriptions of their experiences were included in this book. Finally, Minichiello et al. (1990) suggest that researchers use an interview guide that suggests the type of themes, topics and questions for discussions with participants. Based on this suggestion, I developed and used an interview guide for use with participants. My interview guide included asking people about how they got their brain injuries, sharing my story and asking people about the ways in which their brain injuries had affected them.

Another interview technique expounded by Minichiello et al. (1990) was the use of probing questions. This strategy involves statements like:

> Tell me more . . .
> Go on . . .
> What happened then?
> What did you think and feel about that?
> Why do you feel that way?

The use of probing questions is a particularly useful device in interviewing brain injury survivors, because often they need a little more time to get to the main point they want to make. In fact, many brain injury survivors have difficulties with providing sufficient information in a conversation (Snow, Douglas and Ponsford, 1998). I have found that developing my probing skills has allowed me to conduct much better interviews with other survivors. Also, I have found that by having long-standing relationships with people and by holding many formal and informal conversations with them, I was able to understand their personal communication styles better. As well, knowing people's families meant that I inevitably had a more thorough knowledge of the individuals as well. Family members might say something in passing that seemed important to me, and I would sometimes ask the survivor about that issue later. This was another way of finding more about the person. By spending a long period of time with each individual and getting to know them and the important people in their lives, I was also able to avoid the problems that some interviewers have reported about not getting sufficient information from their interviews with survivors.

Perhaps the main lesson that I learnt in researching this book was to respect and accommodate the vulnerability and emotional fragility of brain injury survivors, including myself, by putting in clear safeguards during the interview process. My first pilot interview was extremely traumatic and taught me many lessons in this regard. The literature on brain injury often acknowledges that the nature of some people's injuries makes them act in certain ways which may not be socially acceptable. This has been well documented in Chapter Two. However, in the process of conducting the pilot interviews, I came to realize that this behavior (which is euphemistically called "challenging" behavior) needed to be recognized and accommodated within the methodology. Responding to "challenging" behavior in appropriate ways was both difficult and absolutely essential for this research to be effective. The first pilot interview was particularly difficult, as a participant tried to rape me. After that experience, I read widely about safety in research and followed some of the suggestions of Craig, Corden and Thornton (2000), namely: planning for safety in terms of interview sites, being "seen" interviewing people, being more aware of body language, and developing strategies for handling "risky" situations. I would be more alert to warning signs of the influence of illegal substances, and would have contingency plans in place. It was important to ensure the other participants, and myself, were free from harm. This meant I was better able to deal with subsequent "challenging" behavior such as unexpected swearing or abuse.

Even though I tried to be prepared for every situation, I still learned this lesson the hard way—through experiencing abuse from other survivors. At various times, I was sworn at, threatened, harassed over the telephone with late night and early-morning phone calls, my property was destroyed by other survivors in fits of rage, and (as I noted above) I was subjected to an attempted rape. Some of these experiences led me to discontinue my relationships with those particular survivors. But making that decision to discontinue contact meant that I had to think a great deal about the social isolation of those individuals, and whether I was in fact now contributing to their "oppression." I realized that I may have indeed been making them far less supported, but I prioritized my own emotional needs and vulnerabilities. This was a painful emotional process for me.

I was tempted to describe a few of my own personal experiences in this area, and to detail the difficulties I encountered sustaining relationships with some brain injury survivors, in order to present a more complex picture of conducting research around brain injury. I have chosen instead to discuss these issues in more general terms since I am trying to emphasize principles over personalities. I am thinking in particular of some cases where individuals in the study displayed severe paranoia, aggression, disinhibition, swearing, occasional violence, stealing, vandalism, lack of empathy, or other anti-social behavior. Sometimes this behavior was directed towards partners, family and friends. Sometimes, it was directed at me. Often these behaviors would have negative long-term consequences on relationships. I absolutely recognize that some of these behaviors simply require accommodations—such as increased appreciation of non-standard and transgressive behavior. Unfortunately, I have seen such non-standard behavior shunned in many arenas, including disability conferences. But I must acknowledge that some of this behavior goes beyond the realm of "reasonable accommodations," and that it would be unfair to position all resistance to such behavior as "oppression."

"INSIDER" RESEARCH

This project has often been positioned as "insider" research. As Zinn (1979: 209) comments, "insider" research is particularly appealing when people feel that distortions have occurred because frameworks and conceptions have been imposed "from the outside." The idea of an "insider" writing about brain injury appealed to many of the participants because they thought I was more likely to "set the record straight." They expressed a desire to explain what it is like standing on the "inside" looking out, rather than vice-versa. However, I was conscious that I could be engaging in what Thapar-Bjorkert (1999) calls "negotiating Otherness": researchers stand positioned in ways which are mediated by age, education, and social position and there is always a danger that research can be "manicured" by the researcher's position and discursive frame of reference.

I certainly shared a number of characteristics in social interactions which other survivors could relate to and understand. For instance, I had arranged to meet one of the participants at a coffee shop, and although I knew her, I was stressed that my memory would let me down and I would not be able to recognize her. I said to her "I was worried that I wouldn't recognize your face today." She replied "I was worried that I wouldn't recognize your face!." I answered "But you did!" and we had re-established a sense of rapport. Likewise, I often became disoriented and lost when I traveled to participants' homes, and they would regularly reassure me that such experiences are common for those of us with head injuries. My journal reflects such an experience:

> I found getting there via public transport hard because I couldn't remember the name of the road I was travelling on, on the bus. It turned out to be Musgrave Road. I knew that I had to get out at Wentworth Rd. When I saw the Wentworth Rd sign, I pushed the button. It was about a 200 metre walk to Cliff's house. When he asked me did I have any problems finding the place, I said that I'd got a bit confused when the streets merged, because I half expected to see the Army Barracks, but that was the wrong road. He understood (common experience of getting lost a lot).

Another story from my journal reinforces this sense of collective identity among the group. When I visited Kirstyn, she said that she had told her next-door neighbor that I was coming over, and that we were going to write a book. She said he asked "Is he a brainy?," meaning a brain injured person, and she said that I "wouldn't get a foot in the door" if I wasn't. Again, my journal records that one time Reg told me "non brain-injured just don't get it." Likewise, my journal records that Helen noticed the problems I was having trying to push the buttons in the tape recorder and said that she had the same motor control problems from her brain injury.

One participant in this study, J, told me that he had no faith in traditional research:

> Yeah, well after my injury, I don't trust anyone. That's just a built-in thing after you've had an injury—or that's my point of view. With professionals, you can't trust them as far as you can kick them. Listen, as Mark and I said before, they do not know. We're the ones living it. We're the ones with information that they want, and that they can say

> hey you know, we've worked out and done all these things. No one's actually told professionals about. Picking our brains. But when our use runs out, we're nobodies. I mean more so. When they want information it's marvellous the amount of co-operation you can get and do get, when they're after something. And as an injured person, you need to learn to use that to your advantage. Because all they're doing is using you.

While he outlined a critical perspective on traditional research, he indicated to me that there was more trust between us. He told me I was welcome in his house any time. My journal notes one incident which I felt revealed a lot about our relationship:

> Half–way through our talk, I got muddle-headed. J said "Are you brain damaged?." I said "Yes," he said "So am I." We both laughed. That was typical of the night. We had a lot (LOT) of laughs, there was mutual teasing, the air was very informal, and overall we all had a great time.

Although I concede that such narratives may suggest a sense of shared experiences, I am wary of making too much of being an "insider." Styles (cited in Hammersley and Atkinson, 1995: 109) argues that claiming "insider" or "outsider" status is often an element of moral rhetoric which seeks to assert that only certain people are fit to undertake legitimate social research. I find this moral rhetoric unsatisfactory. My own reservations about positioning myself as an "insider" with access to unique knowledge have been discussed briefly in Chapter One, but I shall outline them in more detail here. My position is best described in a quote by Haraway (1991: 184):

> . . . no insider's perspective is privileged, because all drawings of inside-outside boundaries in knowledge are theorised as power moves, not moves towards truth.

Although Haraway does not endorse this view, her comment reflects the position I have taken. My only disagreement with this statement is that I would put quotation marks around both "insiders" and "truth." I begin from a position which problematizes identity. In this respect, I have been influenced by Postcolonial literature. For instance, Bryan (2001) has studied black support groups and argued for a reconceptualization of "black identity" so that the differences between the ways individuals position themselves and hegemonic constructions of their identity are explored. She stresses that the struggle for hegemony is played out not only at national or international levels, but also between individuals and groups. "Black identity" is far more complex than a simple black/white dichotomy might suggest. I feel that a similar argument can be made with respect to disability identities.

I believe that it is important not to position "insider/outsider" status as a fundamental dichotomy, where "outsider" research is characterized as objective and detached and "insider" research is characterized as immersed and subjective. Nevertheless, some of the literature does imply such a dichotomy. For instance, Evered and Louis (1981) suggest that "insider" and "outsider" methods involve a completely different role for the researcher, a totally different relationship to the setting, a fundamentally different type of knowledge and the use of different sources of data. Likewise, Mitchell (1998) seems to suggest that being perceived as an "insider" is fundamental in terms of emotional attachment, objectivity, trust, access and rapport. I do not agree completely with this argument. I do concede that "insiders" may have grappled with the emotional aspects of an issue far more than other people—as Farnsworth (1996) has eloquently demonstrated in her "insider" research into the loss of a child. This emotional energy may enable a careful researcher to be better able to establish emotional connections when sensitive issues arise. Farnsworth (1996) commented that by sharing her own experience of losing a child with parents in a similar situation, and then by ensuring that she was a sensitive listener and collaborator, she was able to identify and integrate many personal, empirical, theoretical, practical and spiritual dimensions of the topic into her work. Participants revealed that they felt it was easier to forge connections with her because of their common ground.

It is not useful to see "insider"/"outsider" status as an absolute, fundamental and static dichotomy. I think that approach is too rigid and inflexible. I am more convinced by the arguments of Christensen and Dahl (1997) who argue that the "insider"/"outsider" category should be viewed as a continuum rather than a mutually-exclusive dichotomy. As they point out, even the degree of "insiderness" may vary between members of a group. They also suggest that the extreme endpoints of being an "insider" and an "outsider" probably exist more in conceptualization than in fact. It seems best to acknowledge that both "insiders" and "outsiders" can contribute to knowledge, and both can use various methods to do so.

Another point which needs to be considered is whether the act of doing research has made me an "outsider" as well as an "insider." Webb (2000) suggests that it can be very difficult to be both an "insider" and a researcher, because it is hard to move from being a participant (even a thoughtful and conscientious one) into someone who has the emotional distance to critically examine what "insiders" are doing. She suggests, however, that "insiders" who are able to engage with and critically scrutinize the data are able to both identify major themes which have emerged and identify their own impacts on the field. Indeed, Webb (2000) concludes that researchers who do not discuss their personal influence on their reports are being dishonest or disingenuous.

Zavella (1993: 53) argues that researchers who study their own communities "should realize that we are almost always simultaneous insiders and outsiders" because we have two audiences—an academic one and a community one. Nevertheless, she argues that researchers in this position have a number of advantages in studying their communities:

- We are more likely to understand complex internal variations in the responses of subjects;
- We are better able to understand the complexities and nuances of language use;
- We hopefully will not be duped by research subjects who create performances for their own reasons;
- We are more likely to be trusted by the research subjects;
- We may find it easier to gain access to the research site; and
- We are more likely to be sensitive in framing questions that respect community sensibilities.

However, Zavella (1993) also stresses that "insider" researchers also have unique constraints, such as the need to be accountable to the community they are studying. These constraints can create personal problems and ethical dilemmas for "insider" researchers. As well, Zavella (1993) suggests that "insider" researchers need to problematize and deconstruct their own sense of identity so that they can identify nuances within the responses of research subjects. She states that rigorous "insider" researchers must self-consciously reflect upon their status within the field site and examine their status in terms of social and power relations within the group.

It is certainly true that people who are positioned as "insiders" seem to experience both advantages and disadvantages as a result of their perceived identity. Some of the advantages identified by Mitchell (1998) in his "insider" research were that he was not "coming in from the cold" on the subject and access to informants was often easier. People trusted him because they knew his background. Coghlan (2000) also suggests that one advantage an "insider" has is their valuable knowledge of the culture, norms, traditions, power blocs and informal structures of the group being studied. However, this can also mean that some "insiders" find it difficult to step back from the group and critically assess it. Similarly, the desire for change can mean insiders are more empathetic and it may sustain their motivation, but it can also mean that researchers draw erroneous conclusions because of their bias. Coghlan (2000: 10) states:

> . . . in trying to sustain a full organizational membership role and the research perspective simultaneously, insider researchers are likely to encounter role conflict. Insider researchers' organisational role may demand total involvement and active commitment, while the research role may demand a more detached, more theoretical, objective and neutral observer position.

Coghlan's argument is flawed, not only because it under-estimates the reflexivity of "insider" researchers, but also because it positions "insiders" and "outsiders" as binary opposites:

> Insiders can be accurate reporters of their experience, even though they may lack a perspective that outsiders may bring. As cognitive, reflective beings, humans are able to reflect on themselves and their lives, allowing for insiders to be outside observers and reporters of experience. In the same way, researchers are not true outsiders because they are enculturated members of a society (Christensen and Dahl, 1997: 278).

Smyth and Holihan (1999) agree that "insiders" presenting their findings to an external audience need to focus on issues of validity to be convincing. They argue that "insider" researchers must place particular emphasis on subjectivity, bias and ethical issues, including coercion and anonymity, in order to produce research results which are considered credible. They also suggest that "insider" researchers are often in informal and formal positions of power which places both constraints on, and opportunities for, access to people, processes and information. Highlighting the need for attention to working relationships and personal alliances in "insider" research, they suggest that "insider" researchers should be open about the contradictory pressures they sometimes face:

> The risk to the value of the research is not so much that the researcher may not receive or see important information because of the nature of their organisational membership and the relationships she/he has developed, but that she/he will see more . . . (the risk) may be that the insider

> gains access to organisationally sensitive information and risks exposing previously undiscussable issues, disturbing arrangements that serve particular people or purposes, confronting others with less than welcome observations regarding organisational practice and surfacing and naming ethical dilemmas (Smyth and Holihan, 1999: 2).

Certainly, I have felt some of these pressures during this research project. By knowing the members of the group personally, I have been told about many experiences which other researchers would never uncover, such as issues of childhood rape, substance abuse, domestic violence, issues with sexuality and other issues which are frequently kept private. And I have shared similar information about myself with members of the group. I felt that this level of honesty and openness needs to be acknowledged and have included some of my own experiences in the data to illustrate similarities and differences between myself and other participants. There are unique pressures which an “insider” faces regarding self-disclosure. Just how revealing an “insider” chooses to be about various aspects of their lives will have an enormous effect on the data obtained in interviews. Personally, I have tried to balance the responsibility to be honest in the research with some consideration for my own safety and privacy. I have not disclosed everything that I possibly could about the most traumatic experiences in my life, though I certainly have disclosed a great deal.

I have read widely on “insider” research in preparing for this book. Landsman (1998) discusses her “insider” research with mothers of disabled children and argues that “insider” researchers must recognize themselves as positioned subjects in relation to age, class, gender and race. The notion of positioned subjects includes a recognition of the fact that life experiences both encourage and inhibit certain insights. Her identification with the research subjects was on the basis of some shared experiences, raising a child with a disability. However, she also notes that many of her research subjects had different backgrounds from her in terms of class, education, ethnicity and religion. Landsman (1998) suggests that as positioned subjects, “insider” researchers should pay attention to the differences as well as the similarities between themselves and the research subjects. I hope that such differences have been sufficiently acknowledged in this book.

AN “EMANCIPATORY” DISABILITY STUDIES FRAMEWORK

This book has been heavily influenced by the literature on “emancipatory” disability studies. Although (as I have noted in Chapter One) this framework is highly problematic due to its essentialist characteristics which promote one vision of "emancipation," it has nevertheless had significant impact on disability studies and deserves detailed consideration in a book of this kind. Stone and Preistley (1996) have identified six core principles of "emancipatory" disability studies:

1. The use of the social model of disability as the epistemological basis of the research.
2. Overt commitment to the struggles of disabled people and the surrender of any claims of objectivity and neutrality.
3. A commitment that the research will be of practical benefit to disabled people and/or will help to remove disabling barriers.
4. The evolution of control over the project to ensure accountability to disabled people and their organizations.
5. Acknowledging the personal as political, while at the same time identifying common collective experiences.
6. Adopting a plurality of data collection and analysis methods in order to respond to the needs of disabled people.

I will now examine the techniques I have used to ensure that my work is consistent with these principles.

Use of the Social Model

Stone and Priestley (1996), echoing the earlier work of Oliver (1992), position the social model as central to "emancipatory" research methods. Certainly, this book has engaged with the social model, even if it has highlighted some deficiencies in this approach. The social model is therefore an important heuristic device for this book. The contribution of the social model to the politicization of disability is incredibly significant. Nevertheless, it is important to also acknowledge that in Australia, where this research was conducted, the social model is far less influential than in Britain. It is seen as the movement's "big idea" in Britain (Hasler, 1993), but in Australia it has not achieved this sort of dominance. I have registered my unease with the social model as a grand narrative in Chapter One. However, I do acknowledge its political importance and I have engaged with it at some length, particularly in Chapters Three and Six.

Siding with Disabled People

One of the main problems with traditional disability research was that researchers failed to ally themselves with the disabled people they were studying. For instance, while passionate and articulate disability activists like Hunt (1981) emphasized their oppression in segregated institutions and stressed the need for disabled people to be supported to live in the community, researchers such as Miller and Gwynne (1972) simply argued for changes that would make the institution more effective places where disabled people could undergo the transition from social to physical death. The demand for informed and partisan disability research grew out of such oppressive experiences. In their excellent examination of the methodological issues surrounding disability research, Moore, Beazley and Maelzer (1998: 56) argue that:

> The chief lesson to be learned . . . is that a research approach which places disabled people at the centre of its processes and analyses is essential . . . unless disabled people are listened to from the earliest stages of a project, opportunities for researchers to respond effectively to their input are minimised.

I take these comments very seriously indeed and I have made every effort to discuss this research project with other disabled people. However I am also aware of some feminist arguments which identify a deep-seated inequality between researchers and informants which cannot simply be overcome by identifying with the research subjects (Jaschok and Jingjun, 2000). In order to provide a more rigorous analysis, I have therefore asked brain injury survivors to provide me with critical feedback through every stage of the research process. I felt this sort of feedback was necessary to ensure that the research would benefit other disabled people (and particularly brain-injury survivors) rather than just myself. I have always wanted the research to be of practical benefit to other survivors. I also wanted to acknowledge the unique insights that other survivors can offer to a project like this, particularly by providing them with an opportunity to highlight the inadequacies of government responses to (and medical explanations of) their experiences. I was also aware that their involvement would greatly enhance the personal, practical and policy relevance of the research.

Once I started to think about having a group of people with brain injuries as key participants in the research process, I faced a number of ethical dilemmas. I know personally that as a brain-injured person, I have been used as a “guinea pig” for many research projects, having to answer questions and having various wires strapped to my head, and have often felt used and degraded in the process. I have never seen any of the reports that were written, or the research findings, from any of these projects. I did not want this research to be yet another time when disabled people are asked to “tell it like it is” when the researcher was the only one who would benefit and nothing would really change for brain-injury survivors. For me, the only way that I could get around this problem was to follow the following strategy:

- encouraging other brain-injury survivors to be involved;
- declaring a clear commitment on the side of brain-injury survivors;
- having an underlying element of trust with the other survivors;
- being open and honest about my intentions in the research and its aim to break down barriers that disable us;
- establishing clear boundaries which identified what was and what was not part of the research;
- agreeing to respect the privacy of participants;
- giving everyone the opportunity to comment on and revise working drafts;
- giving everyone the opportunity to see both their words and drafts of the complete manuscript before publication;
- giving a commitment to advocate for changes identified by the group;
- broadly disseminating the information written by the group;
- recognizing the right of every member of the group to be heard and to be listened to; and
- having long-term, honest relationships with group members that extended beyond the scope of the research into a genuine interest in them and their lives.

I hope that these principles meant that our collaborative approach would avoid the oppressive pitfalls of the traditional approach. I felt that using this strategy meant that my work approximates in a small way the goal for "emancipatory" research set out by Oliver (1992: 111):

> The issue then for the emancipatory research paradigm is not how to empower people, but once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose.

I also want to acknowledge that this research would not have been possible at all without the friendships within the group. While I am not trying to romanticize the concept of friendship, such bonds within the group have provided a source of support and have to a great extent overcome any possible isolation for me as the researcher. As well, I believe friendships encourage more honesty, particularly in a context where people are asked to be open and honest about their criticisms. These friendships, and my personal and political commitment to the participants, also meant that there were some unusual elements in my relationships with some people. For instance, one of the participants was over-stressed and came and stayed at our house, on one occasion for five days and another time for three days. A few overnight stays, following a meal, occurred for another of the research participants. Almost all of the participants have been guests in my house for parties, or for dinner, at one time or another. I did not use these occasions as opportunities for "data collection," but I feel that they need to be acknowledged in order to give an accurate representation of my relationship with the participants.

Utilizing Non-Hierarchical Relationships in Research

It has been suggested that in order to create more "emancipatory" forms of disability research, it is necessary to ensure that the relationship between the researcher and the respondents is non-hierarchical (Lloyd, Preston-Shoot, Temple and Wuu, 1996). Barnes and Mercer (1997: 6) have provided an excellent critique of the traditional social relations of research and the idea that a researcher can be the "expert" in disability:

> The power of the researcher-experts is enshrined in their control over the design, implementation, analysis and dissemination of research findings. As a consequence, the 'subjects' of research are treated as 'objects,' with little positive input to the overall research process. The emancipatory paradigm rejects the notion of researcher-experts moving between projects like 'academic tourists,' and using disability as a commodity to exchange for advancing their own status and interests.

While the notion of an "expert" researcher runs contrary to the principles underlying "emancipatory" disability studies, it nevertheless is difficult to conduct any form of investigation without the researcher gaining some degree of power (Griffin, 1995). It is also difficult to ignore the fact that I am going to be the main beneficiary of this research. This is a particularly difficult point given that a major emphasis of "emancipatory" disability studies is on "reciprocity, gain and empowerment" (Oliver, 1992: 111). Perhaps a research project conducted towards an individual's degree can never be truly "emancipatory." I have nevertheless tried to ensure that the book still meets the goals of reciprocity, gain and empowerment by acting in a collective manner with other brain injured people, by working alongside them in the struggles that were important to them, by using an empowering process (self-advocacy as well as collective action), by identifying individual unmet needs among participants and by focusing on outcomes which would make all of our lives better. As Stone and Priestley (1996) comment, the goal is an environment where disabled people are empowering themselves through participation in every stage of the research.

I feel that it was probably easier for me to achieve a significant level of trust and rapport with research participants because I have been very open about my own experiences and have often asked for emotional support and help from the group during my recovery. Also, other factors associated with "insider" research encourage more participation. I often position myself as a "survivor," I relate to other survivors on the basis of shared experiences and mutual respect, and I know the other research participants through our brain-injury group, so we are used to collaborating together. I have made every effort to have healthy and positive relationships with these other brain injured people, mixing socially, learning from others and having dialogue about ideas and assumptions. I also hope that by shedding professional power and mystique, the research will be more relevant to other brain injury survivors.

Self-exposure

One of the criticisms of traditional research practices is that the researcher never exposes as much of themselves to the research participants as vice-versa (Oliver, 1992). "Emancipatory" disability research has sought to challenge this imbalance and replace it with a notion of reciprocity. I agree with this principle and have made a great deal of self-exposure to the other brain injury survivors. In part, I think this is because my brain injury makes it very hard to keep even small secrets; self-disclosure comes much more naturally. Another contributing factor could be that my whole sense of what is "private" has been fundamentally violated by having literally hundreds of people from various occupations (doctors, medical students, nurses, physiotherapists, neurologists, neurosurgeons, university researchers, psychologists, psychiatrists, orthopedic specialists, rehabilitation counselors, neurophsysiotherapists, neuropsychologists, occupational therapists and many more) investigate virtually every element of my mind and body. However, I also think that in this context, self-exposure is a very conscious choice which I saw as a necessary part of sharing both positive and negative experiences.

I will now summarize many of the topics which I chose to disclose to the other brain injury survivors. I will do this in order to indicate the level of honesty and disclosure which I believe "emancipatory" researchers (particularly those doing "insider" research) ought to use. The sorts of personal challenges I have discussed with other survivors include memory problems, dizzy spells, fits, near-death experiences, depression, problems dealing with stress, lack of motivation, troubles returning to work, mood swings, identity and self-esteem issues, disinhibition, difficulties dealing with doctors, lawyers and rehabilitation counselors, confronting prejudice, and dealing with discrimination. Many of the other survivors have shared similar stories with me. I saw such self-exposure as a reflection of the reciprocity in the relationship. My own experiences are included in the data in Chapters Five, Six, and Seven as a reflection of my commitment to the participants. They expressed a desire for my story to be included alongside their own.

Self-Critical Reflective Practice

Barnes and Mercer (1997: 7) comment:

> . . . emancipatory research in the disability context should be enabling not disabling. It must be 'reflexive' and self-critical lest a new orthodoxy is established which turns 'doing disability research' into a technical routine. Disability research must not deteriorate into propaganda: it must be politically committed but rigorous.

In line with this emphasis on reflexivity, a major part of my book has involved self-reflective thought about my role as a researcher. I agree with Barnes and Mercer that being self-critical about personal assumptions, values, practices and beliefs is a vital ingredient of any rigorous research process. One of the major choices which I made was to decide whether I was going to be a passive listener, with no acknowledged political agenda, or whether I would clearly and actively state my political position from the outset. I chose the latter option, and stated my position clearly to other survivors and their families. I am strongly motivated to oppose injustice when I see it, to acknowledge and value diversity when I encounter it, and to pay attention to individual difference when I am aware of it. This has meant that I have sometimes disagreed with some of the positions adopted by other participants.

Feminist literature has been very helpful in terms of developing an understanding of where it is appropriate to challenge the views of participants. Luff (1999: 693) has described the dilemmas she faced as a feminist researcher working with anti-feminist women:

> . . . the process of my research involved striving to deal with the participants' subjectivity, enabling them to express their views as openly in

> their own words as possible, and involving them in some feedback in the analysis stage, but it did not go so far as to involve them in interpretation. In this process, the intricacies of developing and maintaining rapport with the women, and the negotiations of power felt at times complex and uneasy.

In some respects, I faced similar problems when participants in this study adopted sexist, racist or other political positions which I opposed. For instance, one man wanted to contrast the "deserving" status of disabled people with the "undeserving" status of single mothers. This was his political agenda, not mine, and I found it oppressive. Similarly, others wanted me to adopt racist positions, such as labeling certain people "wogs," which I could not condone. So at the level of analysis, I made a quite firm stand to position myself as "somewhat independent." When tensions arose between adopting oppressive discourses and distancing myself from the participants, I chose academic independence and distanced myself from the oppressive discourse. Not only did I feel morally compelled to take this position, I think this independence was also necessary given the depth of the theoretical debates which I hoped to address in the book.

CONCLUSION

In this chapter I have outlined the methodology which has been used in this thesis. I have adopted a qualitative approach to the study of brain injury and have conducted an intensive study with a small group of brain injury survivors. The chapter has positioned this study with regards to the theoretical context of "insider" and "emancipatory" disability research. Ethical and methodological issues associated with the research have also been discussed. The next chapter will consider some of the data obtained from the study, indicating the nature of the impairments which participants have experienced.

Chapter Five

Our Impairments

INTRODUCTION

The purpose of this chapter is to summarize the impairments experienced by the members of our group. This chapter provides data which parallels the discussion of ABI as an impairment in Chapter Two, which outlined various effects of a brain injury, including cognitive and personality changes which can effect social skills and basic living activities, as well as communication, community involvement, work experiences, and sexual activity. The chapter focuses on the nature of the injuries our group members experienced and the myriad of challenges we members have faced—including learning to walk and talk, learning to feed ourselves, and learning new techniques to manage everyday situations (memory techniques, organizational techniques, communication skills, and so on). The chapter also explains how we received our brain injuries, in order to demonstrate that we are quite a diverse cross-section of brain injury survivors.

THE NATURE OF OUR IMPAIRMENTS

In this section of the chapter I will outline the nature of the injuries that members of our group experienced. While the medical model distinguishes between mild, moderate and severe brain injuries, largely based on the length of time in a coma, few of our group members describe their experiences in this way. Some do not have access to their medical files, some either do not know, or were not told about their injuries in these terms. So rather than use the medical terms, "mild, moderate and severe," in this chapter the individuals who have been interviewed will choose their own ways of describing their injuries. They will explain what their brain injuries mean to them, in real, concrete terms. In general, the inclusive term of "brain injury survivor" is used, rather than the medical terms such as "stroke victim" or "traumatically brain injured victim." Some of our group received traumatic brain injuries, while others received theirs through strokes, heart attacks, and other ways. But we find the term survivor to be a broader, less medical and more inclusive term, and one that encompasses our theme of recovery from an experience that changed us forever, and could have killed us.

Cliff received his brain injury through a ruptured aneurism and stroke. He was under the influence of drugs at the time, and spent some time in a confused state before he received medical treatment.

> I had just a mild stroke I think which was brought on by an aneurism, like a collection of blood vessels in my brain that basically shouldn't have been there. Yeah it was a birth defect so yeah. After that I had endless you know time in hospital . . . I had—well first they you know, relieved the blood from the brain and everything. Yeah, next off they put this nasty big scar on my head. They went in my brain and chopped all the aneurisms out and so forth.
>
> *So there were a few?*
>
> Yeah oh well no there was only the one apparently but like I said, there was the collection of blood vessels.
>
> *So they chopped the blood vessels that shouldn't have been there, is that what you're saying?*
>
> Yeah, yeah, got rid of them, and then I had a bit of radiation treatment for the remaining bits that were there because they didn't want to go too far unless they'd be starting to get into some serious brain tissue. And they didn't want to go any further just in case other things happened.

Cliff experienced a number of seizures after his brain injury. He also reported problems with his verbal and non-verbal memory—for instance, shopping was a very stressful experience for him as he could rarely remember what he was supposed to buy. He had what the medical model would call some quite severe "executive disorders," for instance, real problems with goal setting. It took him days to work out how he should deal with a fairly routine matter like getting a new keycard from the bank. The planning involved—working out an ordered sequence of how to get there, getting the card, disposing of the old card, and getting home again took him approximately one week. Cliff also demonstrated fixed and rigid thinking—for instance, on one visit to my home he began doing some cleaning, and he simply could not stop for approximately eight hours. No amount of verbal encouragement to undertake different activities could persuade him. On other occasions, I saw him very demoralized and lacking initiation. He told me he could not get out of bed, and when he did, he could not organize things when he was left to his own devices. He tried dietary changes to improve his energy levels but refused to see a psychiatrist or counselor. His previous negative experiences with those sorts of professionals had turned him away from them completely. Another more serious change in Cliff's behavior was the expression of anger and aggression, as well as swearing and verbal abuse, often linked to psychotic episodes and drug taking. He had been in trouble with the law on numerous occasions, often threatened self-harm, and had moved from home to home following violent outbursts. I often saw Cliff experience periods of crying, shakiness, trembling, and other signs of stress.

Some of the people in our group received multiple disabilities, not just brain injuries. Madonna, for instance, explained that other than her brain injury "I had a fractured left wrist, left hand, my spleen was removed, broken neck, right leg broken in seven places. Pin through right leg." Madonna died a number of times, but was resuscitated. Madonna was in hospital for a year and a half and she had a tracheotomy to help her breathe. She said to me, "They didn't think I'd walk again." Madonna lost her sense of smell and much of her sense of taste as a result of her brain injury. I often saw Madonna have problems maintaining her balance when walking or bending over, although she thought that her balance was much better now than it once had been. Madonna's speech was also different after her brain injury. She had damaged the parts of the brain which co-ordinate and control speech muscles so her speech was often slurred or labored. After I spent a considerable amount of time with her it became much easier for me to understand what she was saying, but at first it was quite difficult. Madonna's conversational style was also influenced by her head injury. Characteristically she spoke in short sentences and provided little information unless questioned at length. As I suggested in Chapter Two, brain injuries often cause people to experience significant changes in their communication styles.

Reg's brain injuries occurred in 1983 and in 1984. He had a blood clot on the brain as a result of one of these injuries. He also sustained a fractured skull. He explains:

> I smashed the right side of my face. The whole side of my face was out past my nose, just shattered, blood and guts everywhere.

Reg's head injury affected both his sight and his hearing. He now describes himself as "legally blind, and severely hearing impaired." He identifies as being Deaf. Reg technically died on a number of occasions and was brought back to life. He said that:

> It's amazing, hey? To think we're survivors. We've gone through these things that should've killed us.

Reg's injuries particularly affected his behavior, personality, and executive thinking processes. That is, he often became very agitated and aggressive. He reported frequently being in fights and also suggested that many of the health professionals who had seen him were scared of his potential for violent behavior.

Larry received a traumatic brain injury when he was involved in a car accident with a drunk driver:

> A drunk hit me. He T-boned me from—anyhow I was going through an intersection; he went through a stop sign and T-boned me into the front left quarter of the car. And completely wiped that front out; the front passenger went under the dash. She died instantly. The passenger behind her died later in hospital. There were only two survivors. I was in a coma for a week. I woke up on Christmas Day, which was a great Christmas present for my family because it (the accident) was a week before Christmas. Actually a weekend after my mother got re-married. So basically it was a really good time for them. I didn't get out of hospital until I was 18. It was after April in '78 because I was 17 in '77. Did I say I was in a coma for seven days—yeah I did. I had a lot of . . . I couldn't . . . I had to re-learn how to walk; I had to re-learn how to pronounce words again because of the paralysis down my left side. Because I had the injury on the right hand side of the brain.

Larry was profoundly traumatized by his accident. He says that he sometimes wishes he had died:

> I tell you this, I wish I had died because I wouldn't have to go through all the shit I went through in all these years. I wouldn't have to put up with it. I wouldn't have to struggle. I wouldn't have done all of that.

Larry's injuries were severe, including partial paralysis:

> I had to re-learn how to walk. Because especially with the left leg because it wouldn't operate the way it once did. The same with my left arm. I had to do all the physio stuff and co-ordination and crap like

> that. It was very helpful. Let me think. Did it for—basically most of the time I was in hospital that's what I was doing. Was physio. And that's why I was in there a long, long period. It did however take me a long time to get over the initial injury, to perform the—because I was pretty well drugged up most of the time, didn't know what was going on. Because of what happened. And they kept me drugged up because of the two people that died, they wanted to keep it from me. Didn't think I was strong enough to handle it at the time.

Cognitively Larry experienced a number of changes. He had to develop a system where everything was written down so that he did not forget things:

> Yeah well it's taken years to bloody get it right or to get it up and running—not to get it right—just to get it up and running. See because people are always telling me to write stuff down. And I said oh yeah, yeah whatever, whatever you want to say. My father was the one, he wanted me to bloody write it down and you've got a record of it. I only started doing that in the mid nineties. So it's—I had a very bad. I forget a lot of stuff because I hadn't got it written down and then someone would say something, it'd jog my memory and oh God! That's right. Shit! I've got to do that or I've got to be there. But sadly, I never did that and I missed a lot of appointments and a lot of people. A lot of people were pissed off at me because I'd forget stuff. But the people who were pissed off at me didn't fully understand that I had an injury, even though I mentioned to them on probably one or two occasions. It slipped their mind and I was the one who got in trouble over it. Because I have a very bad short-term memory. If I haven't got it written down, forget it! I will forget it.

Despite developing a system for writing down reminders, Larry occasionally forgot things and on a couple of occasions this led to injuries at work. In one such injury he cut off the tip of his finger.

Some people in our group received a brain injury and no other injuries. For instance Kirsten stated that "I broke nothing. I broke no nothing on me, just the frontal head injury." Nevertheless Kirsten's injury was significant; she was in a coma for twelve days. She reports that her personality changed greatly in that time. She went from a softly spoken woman to a very aggressive and sometimes loud one. She explains that "I was angry. I didn't give a stuff." Kirsten does not remember all the details of her car accident:

> Now all I've been told is that I lost control and with that the car's flipped and I've gone into a ditch and here I am today.

Kirsten said that she was drunk-driving at the time of her accident, and this was common practice for her. She remembers being very angry in the hospital setting—she says that she wanted to be discharged and became angry at the staff when they would not release her. However she was experiencing profound confusion. For instance she said that she did not recognize people who came to visit her in hospital:

> There are people I'm not sure of. And apparently they were mates or they were family. I don't know.
>
> *Couldn't recognise them?*
>
> No.

Kirsten found hospital a depressing experience:

> It is, it's depressing, and I just thought just let me get out, I'll do it myself . . . I wished I did die. I thought I don't want to go through all this rot I really don't.

Chronic sleeping problems were another difficulty which Kirsten faced because of her brain injury. Although she felt fatigued very easily, she could not relax enough to sleep:

> It's something you really can't explain to people who haven't been through it. They say to me go and have a sleep, go and have a sleep. Well I can't sleep! I have to take about eight tablets of a night to sleep. Even then I wake up.

The level of anger in Kirsten's comments, and the violent attitudes underpinning them, is sometimes difficult to accept. For instance, referring to one worker she said:

> Well after about a month I could have, not a problem, put a knife through her. It wouldn't have bothered me. Yeah, I could have knifed her, it wouldn't bother me.

Kirsten also talked about problems with depression and initiation:

> There are times like vacuuming, clean up, I can't be bothered. Not because I can't do it I just can't be bothered . . . I've got to push and

> push and I don't want to do it. Like my bathroom as we speak is atrocious. I can't be bothered.

Kirsten said to me that her self-perception had been associated with her looks, her work, her independence and her cognitive and physical abilities. However, all of these had changed after her accident. She is particularly conscious of her weight gain which has followed her accident.

> Yeah. I was 49 kilos. At 49 I looked good and I knew it. I did, I knew it. I knew I was fairly good. But now, I just laugh at myself. I think, yeah a lot of people are going to be really interested in you. Have a look at you. Not likely! . . . You know my Mum says oh you don't look fat. Oh rubbish! Mum's just trying to stick up you know for me but Mum does it the wrong way. Whereas Dad and my brothers say, 'oh shit yeah have a look at you, you're fat.' I like that when they say that. . . . Because there's nothing wrong with looking at me I know that—except for the bloody thirty kilos I've put on thanks to the medication.

Kirsten feels she has lost her independence by requiring personal assistance from her family. She has had to move to a unit which is close to her parent's house and her dependence on them bothers her:

> And it's not far from Mum and Dad's. And unfortunately now I have to, I have to admit that I need Mum and Dad. I don't like to admit it but I do, I can't help it, I need them.

The changes in Kirsten's work skills and labor force status have also affected her greatly:

> People don't want to know. I mean even my own mother. I tried to tell her the other night last week I got another knock-back for a job, I'm that disappointed. Mum said oh one will come up. I said yeah whatever Mum. I said that doesn't mean much to me. I said Mum listen to me. Do you know the way my mind is now I could not even get a job at McDonalds, and that's serious. And she said oh you could. And I said no I couldn't! You've seen how sometimes they've got to move so quickly, I couldn't do it. Now she's got that in her head. I said I couldn't do it Mum. I said how bad do you think that makes me feel. I can't even get a job at McDonalds.

Another person I interviewed, J, was in a coma for approximately ten weeks. When he awoke, he couldn't walk, he couldn't talk, and he had gone through puberty while he was unconscious:

> I was in a coma for what they told me was about ten weeks. I couldn't walk, couldn't talk. When I came out of it I had nasal gastric tube. Yeah and I had grown a fair bit. I was five foot seven and now I'm about six foot seven inch. I was trying to stand up with the aid of physios. I was scared of heights. I remember that. So it was all new to me.

J explained that, "I don't know what actually happened because I had a loss of memory of about two or three months before my injury." However, he thinks he received his brain injury from an accident while riding his push-bike:

> I was sixteen. I'd left school to attend an apprenticeship as a boilermaker. I used to ride from Ferny Hills to Arana Hills everyday. And then October 26th 1988 I rode home, got home, I had my shower. I suppose I had a fight with my little sister and then I went out for another ride on my push-bike. And then I apparently blacked out, rolled down the hill, across the main road, went high over the handle bars, hit the back of my head near the brain stem.

J's injury was at the back of the brain—the cerebellum. So he speaks with a quite noticeable slur. He feels very awkward around strangers and refuses to answer the phone, because he feels so conscious about his speech impairment. Like many people with an injured cerebellum, his gait is quite distinctive too. He is often mistaken for a drunk person and refused entry into bars, because of this distinctive gait.

Rick was also very severely injured. His wife was told that he would be a "vegetable."

He describes his injury in the following way:

> In late Dec '95 and Jan '96, I was in the M7 Ward in the Princess Alexandra Hospital. I had a severe brain injury from a very simple surfing accident. In early Jan '96, I couldn't even move my feet down in the bed. I couldn't walk, talk or eat solid food. In this period, I had a very scrambled brain and could only communicate by thumbs up or down. I could also draw simple pictograms to try and communicate but with not much success . . . I had multiple skull fractures. These could not be

> seen on the x-rays because of air running around in my brain. This resulted in an artery being pinched off to the frontal part of my brain. (This is the executive section of the brain). On 8th December as a consequence of this clipping off of the blood vessel, I had a big bleed on the brain and I had to have an urgent brain operation. Because of the bleed, I completely lost my ability to walk, talk and eat solid food. I had severe ABI (Acquired Brain Injury). After coming out of Intensive Care Unit (ICU), I was placed in the Critical Care Section of M7. I looked a bit of a mess with half my head shaved from the brain operation. I had staples in my head and had been in a coma from early December to early January '96.

Rick also said that his injuries had profoundly altered his relationships with the people closest to him, his wife and children. His sexual relationship with his wife changed completely:

> Probably there are some things I'd like to return to. Probably one of the things, a difficult thing for me to talk about are sexual relationships are a bit difficult because I can't properly have erections anymore. That doesn't help.

He also said that his relationship with his daughter had totally changed:

> My daughter who I was very close to, couldn't handle it . . . In September '96 she was saying to me that she wanted her whole, old Dad back. I said to her, 'Clare, your old Dad's dead, you've got a new Dad now.' But since then, we're rebuilding a new relationship altogether. It's taken awhile but yesterday it was very good.

Another member of our group, Jill, cannot speak. So her husband Duncan, who is an advocate for her, agreed to speak about her situation. Duncan explains how Jill received her brain injury:

> Jill had a cardiac arrest on the 7th of September 1998. She had lost consciousness and was resuscitated within a minute but only lasted a few seconds before she lost consciousness again. People at the class room where she worked at school had resuscitated her and later on ambulance, which was only three minutes away, had done likewise until she got to Wesley Hospital which made it quite a while before she was resuscitated several times.

Duncan explains that when Jill was admitted to hospital, the medical staff could not be sure whether she would live or die:

> Upon arrival at the hospital they told us that they would hook her on a machine and see what would happen. We weren't sure at that stage if she was dead or alive. They couldn't tell us. So further on, a couple of hours later, she was able to breathe so there was a chance of she being alive. They weren't sure how long for. Later that afternoon she was transferred to Prince Charles Hospital, the cardiac ward there, and that evening—approximately about between six, six-thirty—we saw her hooked up on the machine. They told us the same thing, they weren't sure whether she'd last the twenty four hours. So I didn't sleep that night and the following day I went there and they told us the same story again. After the second day I realised there was something happening because either some intervention from above, or our prayers or whatever, that Jill wasn't meant to go. But she was starting to open her eyes and breathing much freely and the third day she was off the machine. Unfortunately the hospital didn't see any kind of improvement in her. Everything they say could be a reflex situation. So we weren't, I wasn't going to accept that. At that time I think they were telling me to say goodbye to her but I think I would have been stupid to do that.

Another participant, John, cannot remember the exact details of his accident and does not know the nature of the injuries he experienced, because he has never been allowed to look at his medical records. He knows that he was the victim of a hit and run accident. John says that he was "left for dead":

> Well I was 42 years old. It happened in Darwin. I got hit by a car and just left on the side of the road. They never called anybody, reported it.

When I first met John, he was living in a nursing home and he had been there for eight years. I encouraged other people to visit him and members of our group subsequently lobbied to get him support and a home in the community. While loss of memory for the events around a brain injury is quite common, the failure of anyone in authority to ensure that he knew the nature of his injuries, or that he had access to that information, is certainly unusual. Other people's assumptions about his impairment meant that they did not share the information with him, and he did not get to see his medical records. He does not know what date his accident was, and he doesn't know how long he was in a coma, but thinks it was a couple of months. He has no idea how long he experienced Post Traumatic Amnesia. John remembers not being able to walk, or talk, and being incontinent. John still has restricted mobility in his left hand. He speaks slowly and with a noticeable slur, as if his cerebellum was injured, but when I asked him was his slurred and slow speech a result of his brain injury, he said that no, it was because he had false teeth that didn't fit properly.

Steven had a car accident as a young child which left him in a coma for a few days. He subsequently developed epilepsy. He said his epilepsy "developed in childhood and wasn't diagnosed until I was an adult." The nature of his epilepsy has changed over time. Steven describes his childhood epilepsy in the following way:

> When I would have a fit as a child, the form of fit I would have, I would lose my vision, everything would go into colour, and I couldn't think straight during the period of time that the fit was. And they wouldn't accept that there was anything wrong, they thought it was an act, being put on.

Throughout his childhood, his epilepsy was triggered when he was physically stressed, such as in sports. He said that because "it's impossible for another person to see it going on," some people accused him of faking his impairment. However, he finally confirmed his epilepsy when he had a grand mal seizure as a 20 year-old. He says that his temporal lobe epilepsy now means that:

> I move around unconsciously of what I am doing. And with that, that has changed over time. When I first started having them, I was partially conscious of having them and I would recover quickly after. It would leave me sick for a period of time. The nervous system would be in a bad state, as though I had a virus . . . And now when I have a fit, I will go straight into it without knowledge of it and I'd slowly recover and at times not even realise that I've had a fit. You have to explain these things to many people, it's very hard.

Getting a diagnosis of brain injury was actually quite liberating for him, even though it was as an adult—"I was able to give a reason for the fits that I had as a child and show, for example, my family that there was something wrong." He says that he can't imagine what his life would have been like without epilepsy: "I've had the disability all my life, so I can't do a comparison."

Helen also received her brain injury quite a few years ago. She was probably unconscious only for about 30 minutes, and she did not experience a coma:

> It was on the tenth of November 1977, therefore I would have been 23. I was walking on the footpath, a paved footpath. It had very busy traffic on the road. Of course you never remember that last ten seconds before it happens. But from someone who saw it, he said the semi-trailer that struck me actually drove one wheel up over the gutter and picked me up, I think with the tray of the cab—not the front of it. Sorry, the tray of the truck, the truck yeah. It hit me in the middle of the back. It broke my ribs, about an inch from my spine. Just shows you can be lucky by an inch doesn't it? I got an injury from some other part of it. Possibly something else from the truck hit me on the right side of the head and I've got a patch about an inch circular that's got no hair on it. But that didn't seem to correspond with the brain injuries I had because I had a lot of trouble on my right side, which obviously would not be a right-sided brain injury.

I suggested to Helen that her injuries could be the result of a "coup contre-coup," where her head may have been shaken around, resulting in injuries to parts of the brain other than the primary site of the injury:

> That's right, I think it did because apparently it threw me along the footpath, and people had rushed over to me there. I really don't know what happened of course. The earliest memory I've got after that was actually being in the ambulance going to hospital.

Helen said that after her head injury, she has had significant attention and concentration problems, she felt confused and disorientated for months, she still has problems if she is doing too many things at once and she sometimes has problems feeling things with her right hand. She also has trouble sometimes remembering people's names and faces. But she has found many ways to manage these challenges, like using a computer system that prints up reminders for her:

> I can concentrate but I have difficulty if there are too many things pressing on you. So I keep a list of everything I'm doing in a day book at work, and that way if you write down if you have to move onto something else, if you write it down you can just backtrack. And I've got a very good computer system that tosses me up reminders all the time so that's ideal. I mean I'm now quite absent-minded. But you

> know what it's like at the University of Queensland, all your professors are absentminded. You feel at home there!
>
> *So you're dealing with your memory issues by using things like computers, by using reminders, by writing things down?*
>
> But it also retrains. Your memory will retrain. I didn't know it would and I went to a job where I was putting forty to fifty (hours) a week into work, and I found that when I started working at that hard, I could remember the spelling of everybody's names, I could remember their profiles, etc., etc., etc. Whereas one of the early things I had was just being totally unable to remember names.

Helen was officially diagnosed as having a brain injury by a neurosurgeon:

> I did talk to a neurosurgeon. He sat there with a student, he got me to count backwards from a hundred in sevens, which at that stage was tremendously difficult. Although I ended up with the right number at the end of it so I know that I managed it. He then explained that, to the student with him, this was very typical of a certain amount of, certain type of brain injury, and assessed, was saying how long post-traumatic amnesia I'd had, and how long I'd been unconscious. And he suggested that at about six months I would get a very good spontaneous recovery. I did actually get a very good at about five months from some of the confusions and things like that, but there are other problems that are still with me.

A neurosurgeon was the first person to tell me that I had brain damage too. He said to me that I had to understand I had "brain damage" and I would never recover from it. He was the first of many neurosurgeons, neurologists, neuropsychologists, psychiatrists and others to attach this label to me. One of the things which fascinated these health professionals was that the length of my own period of unconsciousness is difficult to determine because the barbiturates I was administered extended my period of unconsciousness. These barbiturates were necessary for the multiple operations which were performed and to assist in the healing process. So estimates from doctors about the length of my period of unconsciousness vary considerably. However, my extended period of Post-Traumatic Amnesia, the injuries to my face, my poor scores on certain types of neuropsychological tests and the organic damage picked up in neuroimaging is consistent with a moderately severe brain injury. This is a diagnosis which I have been given. Secondary diagnoses include a mood disorder and post-traumatic stress syndrome.

At first, my parents were told that I probably would not live. I was in a "critically ill" condition in the Intensive Care Unit. When it became clear that I would live, my parents were told not to expect too much of me. It was suggested that I would never work again. Fortunately, I was not given the label "vegetative." Unfortunately, a number of the other participants in this study were given this dehumanizing label which robbed them of their dignity and their humanity.

I will now document the ways in which such representations have resulted in the denial of rights and opportunities for members of our group. The label "vegetative state" is sometimes considered a lower form of life—recognized as living, but not as human (Winslade, 1998). People who have this label are denied proper rehabilitation because there is no point—they have lost their humanity. Unfortunately for many of the participants in this study, the inaccurate diagnosis of "vegetative state" and the lack of timely rehabilitation may have lead to a worsening of their impairments. For instance, John was given the diagnosis of "vegetative state," so he received no rehabilitation at all. He explained that the hospital "wrote me off" and then he was placed in a nursing home. I asked him what rehabilitation he had received:

> I've had none.
>
> *You've had none?*
>
> Apart from here (being in the nursing home).
>
> *And it would have helped?*
>
> I should have had speech therapy.
>
> *You haven't had speech therapy?*
>
> No.

John said that he had met many professionals since his admission to the nursing home—the home was owned by a doctor who doubled as John's personal physician, and he had received some services from physiotherapists. He had some contact with the hospital as an outpatient but he decided that he did not want anything to do with them because he found their locked ward so oppressive as an inpatient. John's position was rendered even more powerless by the death of his brother shortly after his admission to the nursing home. He had been a ward of the state and he had never experienced a close family. He knew that he had had an auntie but that she had died. So John had no one left to advocate on his behalf. When I visited him on the first occasion in 1998, I was his first visitor in four years. At that time John told me that no one had discussed the possibility of living in the community with him because he had been diagnosed as "vegetative." Simply being labeled as "vegetative" was enough to set in chain a series of events which lead to his incarceration in a nursing home funded by the government. He never had any visitors from the funding agencies to examine whether he had recovered, whether the label was appropriate, and whether community living might have been a more suitable option. He explained that his finances were handled by the Public Trust, he had no access to any medical records, he had no bankcards, and he had no documentation about his identity. "The (hospital) wrote me off and then I come here." He also told me that he had received no counseling even though he had a long-term psychiatric condition prior to his injury. He demonstrated his independence to me as we walked around the nursing home. He was in charge of his own room and he made his own bed, he showered himself and he was free to leave the premises unescorted whenever he liked. We walked to a nearby park and he told me how he visited the gym regularly and liked to go shopping. The idea that a person with such cognitive skills could be represented as "vegetative" made me shudder. It spoke volumes to me about the human rights of people like John who are represented as "vegetative."

John's case is not an isolated one. The Brain Injury Action Group contained many people who had also been given the inaccurate label of "vegetative state." Of course, clinical diagnosis of "vegetative state" is highly controversial and could only be done after a number of months. However, Duncan commented that Jill was given the label of "vegetative state" within three days of her heart attack. When I asked Duncan how long it was after Jill's heart attack that the label "vegetative state" was applied, he replied "third day." I asked him to explain more what happened on that day:

> The third day they told me, the doctor there, the chief cardiologist said she wasn't going to get any better. In fact he said she could get pneumonia and die or other respiratory diseases. Now that was their assumption. They were giving me a time frame that a year's living would be too much.

Because of this label, Jill was also denied rehabilitation:

> By and large we've hit a brick wall immediately because at the hospital they intend to rationalise along the lines that you have a person in a vegetative state therefore you can weep and cry now and then perhaps forget about the person and they just find a place for her or him in a back room in one of the lesser places where human beings live.

Madonna was also given the label of “vegetative state” when she was eighteen years old. Her family was told by doctors that a nursing home would be the most appropriate accommodation for her. They resisted this diagnosis and took her home where they tried to rehabilitate her themselves. Each of them took turns in stimulating her senses. Slowly she recovered and began to walk, talk and experience more opportunities for growth. When I asked her what being labeled “vegetative” meant to her, she replied that it meant people “wrote me off.” I asked her “How do you feel about the people that wrote you off?” She replied:

> I think they’re idiots. They didn’t know what they were talking about when they said that. They said I would be a vegetable, before and after my coma. I used to say to Mum, I want to go up to that doctor, walk in, kick him in the shins and walk out. Cause that’s not a nice thing to say.
>
> *What do think they meant by being a vegetable?*
>
> Wouldn’t walk, wouldn’t talk, wouldn’t think.

As these cases illustrate, representation is a central issue in the experiences of brain injury survivors. Being represented as less than human has enormous effects on the way individuals are treated by the service system and by their friends and family.

Significant factors in the experience of brain injury included the specific areas of the brain which have been injured, the age of the person at the time they received their injury, how the person received their injury, the length of time since the injury and the other injuries which they received at the time. Table 5.1 outlines some of this data for the participants in this study.

It is important to distinguish between people who had closed head injuries and those with open head injuries. The significance of this distinction lay in the fact that oxygen is incredibly harmful to an exposed brain and that open head injuries can be quite localized whereas closed head injuries often involve more diffuse damage. In this regard it is important to note that Rick and Reg had open head injuries whereas all the other participants in this research had closed head injuries. In terms of the sections of the brain which have been injured, our group contains individuals with injuries to their frontal lobe, parietal lobe, temporal lobe, occipital lobe and cerebellum, as well as people with fractured skulls and others with diffuse brain injuries. The majority of people in the group had some damage to either their frontal or parietal lobes, which is to be expected given that these are the most commonly injured

Table 5.1. Details of Injuries Experienced by Participants in this Study

Name	Age at time of injury	Years since Injury	How Received Brain Injury	Details of Injury	Other injuries, complications
Larry	17	22	Traumatic Brain Injury. Car accident—hit by a drunk driver	Coma for 7 days, diffuse injury (especially temporal lobe)	No
Cliff	26	4	Stroke and aneurism. Occurred while under influence of drugs.	Parietal lobe aneurism	Epilepsy
Rick	46	4	Traumatic Brain Injury. Accident on boogy board	Coma for 4 weeks.	Multiple Skull fractures. Burst blood vessel in brain.
Madonna	18	12	Traumatic Brain Injury.	Coma for 3 and 1/2 months, diffuse injury. Cerebellum, frontal lobe and parietal lobe damaged.	Technically died. Broken neck. Broken leg requiring reconstruction.
Mark	25	9	Traumatic and Anoxic Brain Injury	Diffuse damage, including frontal lobe. Length of coma unclear, due to influence of barbiturates.	Serious orthopaedic and internal injuries.
J	16	12	Unsure. Could be Aneurism.	Coma 10 weeks. Frontal lobe and cerebellum injured.	No
John	42	8	Traumatic brain injury—pedestrian in a hit and run accident	Doesn't know—but was given the label "vegetative state"	Does not know

Table 5.1. Details of Injuries Experienced by Participants in this Study (continued)

Name	Age at time of injury	Years since Injury	How Received Brain Injury	Details of Injury	Other injuries, complications
Reg	17	17	Two traumatic brain injuries from assaults	Cerebral haematoma, fractured skull. Parietal lobe damage causing hearing and vision impairments.	Technically died.
Kirsten	27	4	Alcohol-related Traumatic Brain Injury	Coma 12 days. Frontal lobe injury	No
Jill	45	2	Anoxic brain injury resulting from cardiac arrest	"Vegetative State" label applied. Very serious brain damage. Nystagmus	Series of heart attacks, also subsequent pneumonia
Steven	Unsure: occurred as a child	Over 20 years ago			Epilepsy
Helen	23	24	Traumatic Brain Injury	Unconscious for 30 minutes?	Punctured lung

part of the brain. As I noted in Chapter Two, injuries to the frontal lobe are frequently associated with problems regarding aggression, irritability, planning, insight, impulsivity and judgment, whereas injuries to the parietal lobe are associated with sensory impairments. In this regard, it is interesting to note that Madonna has lost her sense of smell and taste, and Reg has acquired hearing and vision impairments due to his brain injury.

In terms of the nature of the injuries sustained by members of our group, the vast majority had traumatic brain injuries, and the others had anoxic brain injuries, alcohol related brain injuries and strokes. The significance of this characteristic is that it means that most of the people in our group were relatively young when they received their brain injuries. If we assume that Steven's brain injury occurred when he was five years old (and this seems a reasonable assumption given that he has stated that he was a very young child when it occurred), then the average age at which people sustained their injuries was approximately 25 years of age.

Another of the factors influencing the effects of a brain injury are premorbid characteristics such as substance abuse. In this regard it is important to recognize that some of the members of our group received their brain injuries while significantly under the influence of drugs and alcohol. Continued use of such substances by people with a brain injury may result in further brain damage and will have other adverse emotional and physical effects. Nevertheless, there are strong patterns of alcohol or drug use among the people who participated in this research. In my calculations, approximately one-quarter of the group currently have substance abuse issues which are not recognized or being addressed in any way.

One of the major difficulties which people in the Brain Injury Action Group have identified is the lack of timely and appropriate information about the impairment. J said that he had to inform himself about brain injury and how it affected him. When I asked him "Who gave you information about brain injury?," he answered simply: "Me!" Larry also said that he was not provided with sufficient information about brain injury. Larry's injury was in 1977, but it was not until the 1990s that he was provided with some information about brain injury:

> When it happened to me in '77, they didn't have the information that we have nowadays. I didn't even become fully aware of what truly happened to me until I went to the Brain Injury Association which had all that information. But no one had that information in the eighties or even in the seventies.

Larry indicated that he had gone without information on brain injury for a period of around fifteen years:

> Yeah without that information, and I didn't know, I didn't fully understand why this was happening or why certain things happened, and why I forgot. I'd always put it down to my injury but I wasn't fully aware that it had had a great deal to do with it because I didn't have the information. And it is true, yes, the information they've got is always gloom and doom for the parents or family. They say oh he's not going to be able to do that, he's not going to be able to do this, and that's the end of it. That's all you can do.

When I asked Duncan about the information provided to him after Jill's brain injury, he explained that the Brain Injury Association had given him a book that was over ten years old, and which was out of date, since many of the procedures for dealing with brain injury had changed in that time:

> It probably had a lot of information that's pretty normal. I think it runs pretty well okay but a lot of other information wasn't relevant. So when I did get in contact with Mark, which was a roundabout way, I found out there was other information that I should look at which made the first bit of information a little bit obsolete.

Duncan and I spent most of one week searching library databases and journals, and posting to neurology discussion lists on the Internet, to find out the most recent developments in responding to someone in Jill's situation, who had experienced both anoxia and a heart attack. Informed with the information from health databases and the Internet, Duncan tried to discuss Jill's situation with medical authorities. Doctors were reluctant to have any meaningful dialogue:

> They have no information, they don't accept information. Maybe you'll send information they throw them in the bin, they don't want to know. The reason they don't want to know is because I think we're encroaching on some of their work and they don't like to be told.

Medical professionals were unwilling to relinquish power and have a meaningful discussion with the advocate of a brain injury survivor in this case. Doctors were unwilling to explain or defend their treatment decisions, and were unaccustomed to having informed advocates challenging their authority. Duncan said that he was informally told by one of the senior nursing staff to "stop causing trouble" with the doctors. Instead of being seen as a concerned and loving husband and advocate, he had been labeled a "trouble maker":

> I think that's another big drawback here. People who follow doctor's knowledge or information or whatever you want to call it, expertise. They seem to think I'm a bit of a torch carrier here, I'm making lots of waves and I'm carrying on about something that I don't see.

Kirsten also was provided with no information about brain injury: "Ah well, as far as I know I got told nothing. Even in Rehab." She added that although doctors told her not to drink for two years after her head injury, no one told her why. She later found out the reason: "The two-year non-alcohol was because that would decrease my chances for like epileptic fits. Well thanks for telling me!"

Until I visited him in 1998, no one had ever provided John with any information about brain injury. When I first spoke to him, he said that he needed such information:

> *Has anyone ever given you information about brain injury?*
>
> No.
>
> *Would it have helped to have it?*
>
> It might help now.

So I revisited John with some books on brain injury. Talking to John, bringing written information, and revisiting him with other survivors and family members seemed to help him understand brain injury more thoroughly. Other members of the Brain Injury Action Group couldn't remember whether they were provided with information or not. Madonna said she couldn't remember who gave her information about brain injury: "I don't know. I think my sister went looking for it. I don't know."

As well, almost all the members of the Brain Injury Action Group feel that they were not sufficiently rehabilitated for life in the community. The contradiction between the community spending hundreds of thousands of dollars to save the lives of brain injury survivors and then leaving them without any support once they are discharged from hospital has not been lost on Cliff:

> If they're going to go to all the expense of saving your life and you know cost to the community of hundreds of thousands of dollars to save our lives, and then they just let you scavenge and you know, leave you by yourself so you're virtually helpless and you have to do everything yourself. So that's the thing that I've got a problem with. You know if they didn't save my life and I was dead and stuff, that'd be fine, I wouldn't be here to worry about it. But I am here, and they should be helping me; give me back my independence and everything else. And I've just had to do everything myself. It really makes me angry actually. Yeah it really does, it really annoys me. Of course I can't dwell on that.

Cliff had a lengthy period of rehabilitation, but this was aimed at addressing his physical challenges, rather than helping him relearn the social skills needed for life in the community:

> I had pretty intensive rehabilitation there for awhile. I was in the PA Rehabilitation Unit—I don't know—probably about five months or so. Yeah so I was in there quite a while . . . And then I was sort of moved back to my sister's in Coorparoo. It was only a walk away, and that was handy. And then yeah so while that was good, they still didn't cover everything. I only had sort of little bits and pieces, dribs and drabs and that. They concentrated on people that were more worse off obviously. They just get you to a point where oh you know, you can virtually go back into the community I guess.
>
> *How could that have been better?*
>
> Probably more focused on living in the community and issues dealing with that. And the real skills you need to survive, prosper, and go on and so forth.
>
> *Like what?*
>
> I don't know. Like probably the basic things—how to cook your own meal.

Larry agrees that his follow-up support was also inadequate for a life in the community. He said he needed support in terms of employment, community involvement, information about brain injury, and help dealing with the everyday challenges of life after a brain injury, but simply received physiotherapy aimed at addressing the physical problems associated with partial paralysis:

> With the physio however, they gave me as much as I needed to get by. They didn't show me any skills to be in a workplace, they didn't get me up to that level. They just gave me enough physio to get me by . . . to survive, yeah. They didn't give me any support apart from that.

Larry stressed that his injury occurred many years ago, when responses to brain injury were less sophisticated:

> I mean it was 1977 and they weren't as knowledgeable as they probably were in the late eighties to the nineties. They just weren't knowledgeable enough to understand the difficulty that people like myself would have had to endure.

J believes that the rehabilitation he received was more about meeting the needs of professionals, and the agencies they worked for, than his needs. J argues that these professionals need to say "they're providing for disabled," but they are really providing very little help for disabled people. He feels that his life was put in the "too hard basket" by professionals who "wrote me off." Overall, he is very critical of the role of professionals in the disability field:

> The more you rave on to professionals, they want to use the illusion that they're actually providing you with help. In actual fact all they're doing is providing a service. That service to get the numbers so they can get paid. It's not about really helping people . . . I'm written off. That's why no one will help me.

Many people with a brain injury, including J, are very angry. Because of this anger, people in our group are often labeled as "challenging" or "difficult." But it would be a mistake to assume that it is inappropriate for us to be angry at the disabling world in which we live. J expresses this clearly:

> Any one know any human beings who don't have a bitch or a say about what they like, what they dislike, and what they want and don't want for them? That's all we're doing mate. We're made to, we're called, yeah, challenged behaviour. You know. We speak inappropriately and that sort of thing. It's crap! We say what's on our mind and what we have is as important as any able-bodied person, and if not more. Because we're one up on them, we already have information given to us through our trials and tribulations of having a head injury.

Nevertheless, it must be recognized that there is a significant difference between justifiable anger at a disabling world and a lack of inhibition which involves aggressive behavior, swearing, and unwanted physical or sexual advances. People with frontal lobe injuries often demonstrate such "challenging" and "difficult" behaviors. Indeed, it needs to be said that our group has experienced many of these sorts of behaviors—from unwelcome sexual advances, to swearing, threats of violence, destruction of property, and so on. Particularly when someone is in crisis, frontal lobe injuries can mean that the survivor may phone people at inappropriate times, damage their own (and other people's) property, act in an aggressive manner, swear a lot and be easily angered and irritated. Such behavior has lead to some members of the group having contact with the criminal justice and psychiatric systems. Even though everyone within our group understands the organic basis for this behavior, such acts have nevertheless lead to tensions within our group. Inappropriate sexual advances are one clear example which have harmed our group cohesion. And although counselors often suggest that you should "separate the person from the behavior," this is very difficult for someone with a head injury to do. Responding to challenging behavior has been a real challenge to group cohesion on occasions.

Sometimes, members of our group are aware when their own behavior has contributed to a breakdown in relationships. In these cases, people apologize and try to repair the relationships which they have damaged. But this issue is complex, because some behavior which seems perfectly reasonable to someone with a frontal lobe injury may seem entirely unreasonable to other people, including other people with head injuries. Our group acknowledges that for survivors, it is incredibly difficult to develop and implement strategies which mean you understand how other people are reacting to your behavior, but the over-riding rule of the group is that no-one must be harmed. We try to provide a supportive environment in which people can learn to understand themselves and their relationships with others more fully.

There are a range of strategies which our group members use to deal with their impairments as we negotiate our daily lives. By focusing on these strategies, it is possible to get a sense of the agency of brain injury survivors—trying to take control of our lives, manage our impairments in a disabling world, and develop positive identities and interesting lives in the process. What I find most interesting is not that people experience significant memory impairments, physical, emotional, behavioral and cognitive challenges (the traditional focus of studies on brain injuries), but that they are incredibly resourceful and ingenious in dealing with these challenges.

Helen's story is interesting because it demonstrates that an individual with a brain injury faces significant power issues and power relationships in the process of choosing whether (and how) to disclose the effects of the injury:

> You're very, very confused, and I'd actually been out on a lunchbreak from work when this happened so I was meant to be covered by workers' compensation. And workers' compensation told me that I had to take the leave without pay and then claim it back from them. And I couldn't afford to do that so I actually went back to work . . . I was working in a laboratory because I had a lot of scientific background. So I was working in a laboratory preparing, pre-preparing all the materials for evening classes. And to follow your scientific things, that's very easy because it's just step-by-step routine and you know it back-to-front. But to get to work was very difficult. I should not have been driving, and my partner had just refused to help out in anyway because he didn't want to have to park the car where he was. So I used to drop the children at daycare, drop him at work, and take the car to work with

> me because I had parking. Then I had to pick the children up from daycare in one direction and drive back to pick him up, and he would refuse to meet me at any particular time. I would have to run around every floor in the building to find him. He was very, very difficult about it. He just would not make any allowance for the fact that I had an enormous blind spot of no short-term memory. And eventually of course I ran up the back of another car because you forget it's in front of you when you check left, then check right, you know, to see what's coming. You immediately have no picture any longer of what's in front of you. So I wrecked the car and it had to go away for weeks on end to be fixed, and then I had to take the kids to school by the bus, train, get off at work, get on another train, catch another bus, and I couldn't get the trains right. I'd wind up getting on an express train and taking the kids with me so I'd just take them to work. And the bosses were no help either, even though they knew, they must have realised what the problem was. And then I'd have to drive someone somewhere to pick up chemicals or go to the saw mill to pick up bags of shavings, because we used to keep all these little white rats for the students to dissect. And I wouldn't be able to figure out how to get there. I'd have to take another laboratory technician with me, who didn't drive, but could remember how to get somewhere. I knew the address but I could not picture how to drive from A to B, even though I had driven there before.

Helen's example clearly identifies the power issues in her workplace and in her personal relationship which structure and limit the choices a survivor can make in terms of dealing with the effects of her impairment.

J was also very clear about the power structures within which a person with a brain injury operates. When I asked him what could have made his journey easier, he said:

> That's a hard one because being conditioned the way we are, it's impossible to think that way, how it could be better. Because in those controlled environments, you're either happy with what they give you or nick off! You cannot challenge their ways of operating or thinking to maybe improve or to improve the development of different ways of dealing with injuries, you know, head injuries. So I mean I honestly cannot tell you.

However, I don't want to give the false impression that our group is composed of poor unfortunate victims who have no agency and no capacity to resist or challenge power structures. In fact, I want to stress that our group has displayed incredible ingenuity on both an individual and a collective basis in dealing with our impairments. Individually, every member deals with memory problems on a daily basis. Remembering where you are, what you were doing, who you were with, why you were doing something and when you were supposed to be doing it is a constant battle, every day of our lives. Each one of us has an individual repertoire of techniques designed to minimize the impact of such memory problems. For instance, Cliff uses a diary in which he meticulously writes every single thing he has done in the day, Larry uses a specific notepad, Helen uses a computer system to remind her, and Madonna has a personal organizer which she uses to structure her day. Similarly, Cliff and Helen both emphasize the importance of diet and alternative health practitioners in dealing with symptoms of their injuries such as headaches, fatigue and low levels of energy. Likewise, Rick says that he had lost a lot of his organizational skills, but he has relearned and compensated for them, by developing a great filing system:

> I organise lots of things. I write everything down. I have a little office at home where I have many, many files. I like filing things. In fact I consider myself a professional filer. My files get so big my family wonders when they're going to stop.

It is also interesting to see the innovative ways we work as a group, to ensure that everyone can participate as much as possible. For instance, we acknowledge that everyone has some sort of memory problems, so instead of asking people if they remember what happened at the last meeting, we find a dignified way of restating what has occurred in the past to remind people. We are also incredibly mindful of people's fatigue levels, and we only hold short meetings, interspersed by regular breaks. We also know that the group may be the only social outlet for some people, so we make time to find out what is going on in their lives. And we meet in places that are wheelchair accessible and also accessible by many forms of public and private transport—buses, trains, ferries, taxis and cars. Likewise, we make sure that people are given plenty of time to consider things—whenever we make a policy decision, we always let people take things away with them and consider it for a reasonable period of time—usually a month. We always have our conversations and documents in Plain English, to make sure that everyone understands them. We find ways of listening to people whose voices may otherwise be difficult to understand—we are prepared to give them time, to ask them to repeat things where necessary, and to restate things back to them to ensure that we have understood what they have said. We use alternative communication formats, such as assisted communication devices, where necessary. Similarly, we are always prepared to go over issues again and again to ensure that people have understood them. And we always give each other reminders about the meeting, so we don't forget it. We talk to family members and include them in our discussions where appropriate, for instance, telling them about meetings and asking them to remember it too. All of this is done within a very accepting and non-judgmental atmosphere, which values the person with a brain injury above all else. In a sense, our group has spontaneously developed a model of inclusive consultation for people with brain injuries.

One interesting lesson we have learnt concerns including people who have language or communication problems. While some members of the group have said they felt uncomfortable around people who use communication boards, or who have significant speech impairments, we have made the rule that everyone has a right to be heard and understood. So we make it a priority to listen to people's points of view, and we will do whatever it takes to facilitate that. For instance, some people tend to rarely speak in public, because they are embarrassed about their voices. So we make time to hear those people in smaller gatherings, such as with one or two other survivors. Then we relay their perceptions back to the group. This means that their ideas are included in our work. Another important element in our communication strategies has been to get to know the individual, including their own personal language styles, and to be able to relate the subject matter in a language that is understood by the person. Using parallels from our own lives and personalizing the content has been a very useful strategy in this regard.

CONCLUSION

This chapter has provided an insight into what our group has experienced, particularly the unexpected trauma of a brain injury and the physical and cognitive challenges associated with such an injury. It also has provided some insights into the incredible determination of survivors to have a better life, and the ingenious ways in which people can adapt to their changed life circumstances. Our remarkable resilience is to be admired. However, we are also vulnerable people. For many of us, it's like we started life all over again, without many of the personal resources which we previously relied upon. Often our struggle for a better life has been made harder by a lack of friends, a lack of support, and discrimination. These broader social experiences are the ocus of the next chapter.

Chapter Six

Our Experiences of Disability

INTRODUCTION

In this chapter the disabling barriers experienced by brain injury survivors will be outlined in some detail. These barriers are well known—as was indicated in Chapter Three, they have been recognized in government policies for nearly twenty years now. That brief review of Government policies outlined consistent themes such as the lack of appropriate accommodation, rehabilitation, community support, and support for family members. Data collected in this study confirms the continuing salience of these barriers in the lives of brain injury survivors.

IDENTIFYING THE DISABLING BARRIERS

The participants in this study experience a number of disabling barriers, including negative public attitudes about disability and brain injury, social isolation, inadequate medical care, problems with the legal system, inappropriate and inadequate accommodation options, disabling services, employment barriers, lack of technical aids and equipment, transport barriers, abuse, and restrictive notions of disabled sexuality. Some of the themes in this chapter (such as the discussion around sexuality) were not discussed in group meetings, but instead were raised in private discussions with participants.

Figure 6.1 records the diagram which the group drew on the whiteboard in the course of these discussions. It records what we were thinking at that time. It is interesting to note that this analysis was not carried out in isolation from the formation of wider strategies by the group, such as breaking away from the Brain Injury Association. Likewise, a great deal of the discussion on this occasion centered around making allies and forming coalitions with other like-minded organizations. The organizations which

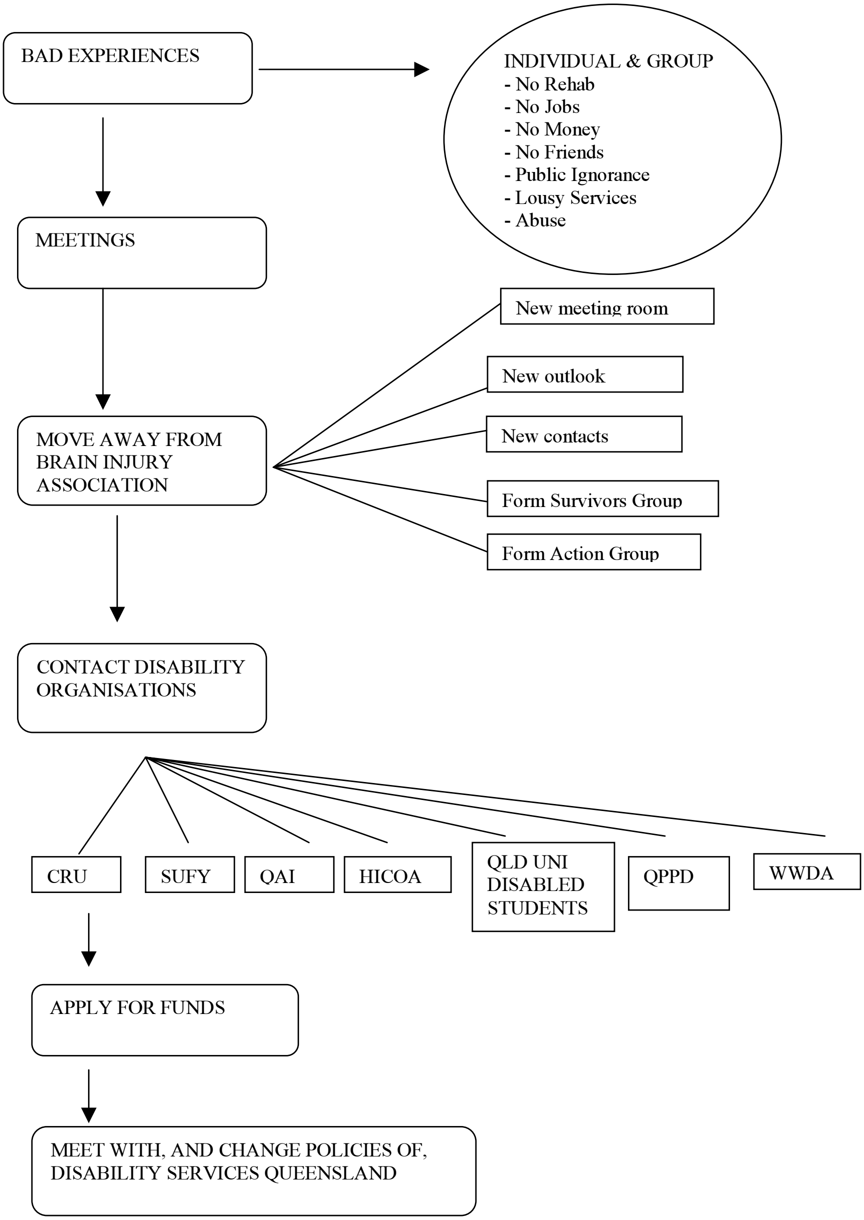

Figure 6.1. Themes Identified in Group Meeting 22 March 2000

our group contacted included Women With Disabilities Australia (WWDA), Queensland Parents of People with a Disability (QPPD), the Disability Collective at The University of Queensland, the Head Injury Council of Australia (HICOA), Queensland Advocacy Incorporated (QAI), Speaking Up For You (SUFY), and the Community Resource Unit (CRU). Again, I felt this approach resembled Oliver's (1992) discussion of "emancipatory" research playing a role in the lives of a group of disabled people who had decided to empower themselves.

Disabling barriers identified in the course of this research included:

- Negative Public Attitudes about Disability and Brain injury;
- Problems with the Legal System;
- Social Isolation;
- Inadequate Medical Care;
- Inappropriate and Inadequate Accommodation Options;
- Disabling Services;
- Employment Barriers;
- Lack of Technical Aids and Equipment;
- Transport Barriers;
- Abuse; and
- Restrictive Notions of Disabled Sexuality.

Negative Public Attitudes about Disability and Brain injury

Public ignorance, apathy and negative attitudes towards disability and brain injury, have consistently been identified by our group as a major barrier which limits our life options and also limits our sphere of influence as a group. Kirsten believes that the public's ignorance of the wide-reaching effects of a brain injury means that they just don't understand what is going on in our minds and bodies:

> And they really don't understand the concept of how and there's so many different little pieces of your life that it changes. You don't know how little, well any abled person would know, well they don't know.

Rick added that one of the reasons why the public finds brain injury so hard to understand is because the injury is invisible:

> It is a big silent epidemic in our community. You can see someone in a wheelchair but you cannot see all the invisibles changes which have gone on with a brain-injury.

Many people assume that brain injury equals intellectual disability, and our members spend a great deal of time and energy debunking such myths about brain injury. We also spend a great deal of time trying to convince people that we are not the tragic victims of fate who want their sympathy, but instead real human beings who want their rights respected and who want to have a life full of options and choices. J says that such attitudes basically suggest:

> Hey you've got a head injury. Just relax, don't try anymore. And personally that pisses me off . . . I know it's not fair , but that's the way it is mate. It's the way it is. When you've got a head injury you've got to become robust, resilient, and become a wall. Just let things bounce off.

Problems with the Legal System

A number of participants expressed their dissatisfaction with the legal system. For instance, Larry said:

> Yeah they didn't have personal injury solicitors back in the seventies. It was just all for the insurance companies. If they didn't have to pay it out they bloody wouldn't. And they won't tell you anything different. And the solicitors at that time didn't know any better. So that's why I was screwed over. Screwed over by the car accident and by the frickin' legal system, yeah.

Helen also reported problems with the legal system. She was profoundly confused after her injury, but no one around provided the support that would have enabled her to make informed choices about her rights and entitlements. No one advised her that she was entitled to lodge a compensation claim for being in an accident. So she did not sue:

> I was not able to think clearly enough to realise that I should have put in a third party personal claim and nobody bothered to do it for me. And it was only years and years later that I realised I should have done it. You know. I think I'm a real stiff upper lip person, and I think people don't realise what problems you're dealing with because you're doing your best to cope with them yourself. And certainly no one ever said hey you were hit by someone's vehicle, you're automatically insured, you should put this claim in. No one offered, no one mentioned it. It was years before I came out of the fog enough before I realised that that was the situation. So I never ever got as far as the legal system.

Social Isolation

Social isolation seems to be a major factor in many people's experiences of brain injury. The discussion of the work of Axel Honneth (1995) in Chapter Three suggested that issues such as love were incredibly important in the process of "intersubjective recognition." Honneth suggests that human beings demonstrate recognition through love, solidarity and rights. In Chapter Three it was suggested that the absence of love was as a major form of disrespect, which disability studies needs to take more seriously. The comments from participants in this study highlight the importance of what Honneth (1995:135) calls "disrespect"—the absence of love, rights and solidarity.

Many people with a brain injury are incredibly socially isolated. Many participants said that they lost all their friends when they had their brain injury. Often "friends" no longer felt comfortable around them, because they had a brain injury. This was interpreted by many participants in this study as one of the most significant forms of disrespect they encountered in their lives.

Madonna's comments about her loss of friends are typical:

> I used to have heaps of friends before, like when I was going to school, and after school. And before my accident I used to have heaps of friends. But after it, no one came to see me at all. When I was in hospital no one came to see me.

Even Madonna's closest friends stopped visiting her after her brain injury:

> Before my accident I used to have heaps, heaps of friends I used to have, heaps of them. And after it, they all stopped, they all stopped. My best friend lives in New Zealand now. She's stopped writing to me. Or I stopped. I don't know. Either she stopped or I stopped. And then after, I didn't have anybody so I was bored, didn't know what to do.

Madonna felt the absence of love in her life acutely. She felt that her accident had made her ugly, and therefore unlovable. One simple comment from Madonna captured many of these issues—"After my accident, I'm ugly. No one will ever love me."

Love is expressed both in friendships as well as intimate relationships. However, the loss of all their friends, as well as intimate relationships, is a common experience for many people with a brain injury. Reg commented, "For two or three years, you're on your own, just when you need them most."

This theme, that people with a brain injury lose all their friends just at the time when they are most needed, is quite common in the narratives of the participants in this study. At that time of need, Reg states "You're by yourself."

J feels that although his friends visited in the very early days after his injury, they soon abandoned him. He is angry and disappointed by the behavior of his so-called "friends":

> In the hospital when you first wake up all around you wishing you well and they're all amassed and all that. But as time goes on, they see that there's not much hope of seeing the old you. They suddenly all disappear. Now when you try and confront people and that, they come up with all the excuses why and that they're slack, and blah-blah-blah but that's the way it is. I can't say why they do it because only they know and they honestly haven't got the guts to tell me or anyone why, why they desert you, you know. It's frustrating but society says, well, gee, I wonder why we have problems? I wonder why we have this attitude towards life? Gee, I wonder.

Kirsten made similar comments about her loss of friends:

> Look I had unreal friends before the accident and I can't think back anymore. I don't think back anymore, I really don't. And I think it's because I don't want to. Why should I? Youse were everything to me. Look just please tell me why? That's all, that's all I want to know. Why youse aren't bothering with me. Sweet! You know, it really won't bother me as much as you think. But they don't. And so with that I try my hardest not to get mad anymore. I've got a birthday coming up next week. That I'm not looking forward to. Okay what do you get? A present off Mum and Dad, a present off your brothers. Big deal! A present. You know, that does nothing for me. That's when I think back. All the things we used to do on my birthday—my friends. I know now I'm not even going to get a card. They don't even know I've shifted units. Some people say oh well you could ring and tell them. No, no I'm not going to tell them. What for?

Kirsten said to me that her lover left her after her accident and she gradually lost all her friends as well. Now her best friend is her cat:

> Now no one would understand what that cat is to me, no one. And even at this stage I'm so scared of anything happening to him. I don't know who else to turn to. I tell him everything, everything I tell him.

> And I have no one to tell anything else to . . . Put it this way, if I didn't have this little cat here which I got in um, he's coming up nine years old . . . Now if I didn't have him, honestly these last few years I definitely would have killed myself without a doubt.

When I asked Larry to discuss the topic of friendships, he simply replied "What are they?" Then he said that while he was still in hospital, many people came to visit him, because he had a wide network of friends through using his CB radio. But afterwards their support fell away:

> But after I got out of hospital, those people that came to see me, we all started to go our own way because they noticed how different I was. And also too, a lot of people that I had as friends, they all got married, and of course being a single person, they didn't want a single guy around . . . So that sort of went pretty crappy for a long while. And then for a long, long period of time I didn't have any friends basically. Oh well no, they were older by at least five to ten years older than I was. But the friends that I had before were a good three to five years younger than I was. And these older people just weren't. I was going to go through what they'd gone through. It's a difficult situation to explain.

Larry's comments are interesting in the sense that they reflect how lack of love in one area of your life can have a snowball effect in other areas. He feels awkward in social situations where everyone else has a partner, and the opportunities for him to socialize are reduced because of his single status. The lack of love on a personal level has a snowballing effect into a lack of opportunities to socialize and make friends. The end result is a very lonely life indeed.

Cliff explained that he too had lost his friends since his aneurism:

> Well I virtually don't have any friends that I used to . . . But oh it's, there's a lot of issues, you know. It's pretty complex. Like issues they couldn't bloody handle and stuff. I don't blame them. I was for awhile there, I was real bitter. But I don't blame them anymore, it's understandable.

Duncan also commented on the abandonment of Jill by her friends:

> Slowly people tend to back off and make you feel as though you're not really all there. That made me feel very sad because she's known these

> people up to thirty years and there they are sort of saying, I don't want to get close.

Even when they see him, her "friends" do not want to discuss her health. "Every time you talk about it of course, they get very uncomfortable and they don't want to know about it."

Unlike many of the other members of the group, John did not have any friends before his accident. He had lived in a state ward as a child, after he had been taken away from his mother's custody. He had a supportive brother, but he had died. John had a psychiatric disability before his accident, had little contact with the other members of his family, and had not made any friends. When I mentioned the topic of friends, John said:

> I have no friends here.
>
> *You have no friends here?*
>
> No.
>
> *Are you lonely?*
>
> No.
>
> *No you're not lonely?*
>
> No.
>
> *How do you cope? It seems to me you're very isolated.*
>
> I'm very isolated but I'm used to isolation. Because I've been isolated all my life.

John was more vulnerable than many of the other members of the group because he had never had any friends, and he did not have a strong family to support him. His vulnerability is evidenced not only by his social isolation but also by the dreadful experiences which he has had during his incarceration in the nursing home. For instance, he watched three people die in his room, and he became so depressed that he tried to throw himself through a window. Although he only received lacerations in his arm from this incident, it clearly demonstrated to me his acute vulnerability and sense of despondency.

The Postcolonial concept of exile can be applied to the situation of young disabled people in nursing homes. Like the exiles who are the subject of postcolonial writings, these people are physically removed from their communities and (unlike voluntary migrants) they still retain some sense of belonging to their homeland community and a nostalgia for a lost past. In John's case, he essentially had no contact with the "outside world" and found it incredibly difficult to escape from his oppressive environment. He had a clear sense of belonging in, and to, the wider community, but he was essentially "exiled" against his will. In *Representations of The Intellectual,* Edward Said (1996 : 48–49) comments that:

> There is a popular but wholly mistaken assumption that being exiled is to be totally cut off, isolated, hopelessly separated from your place of origin. Would that surgically clean separation were true, because then at least you could have the consolation of knowing that what you have left behind is, in a sense, unthinkable and completely irrecoverable. The fact is that for most exiles the difficulty consists not simply in being forced to live away from home, but rather, given today's world, in living with the many reminders that you are in exile, that you home is not in fact so far away, and that the normal traffic of everyday contemporary life keeps you in constant but tantalising and unfulfilled touch with the old place. The exile therefore exists in a median state, neither completely at one with the new setting nor fully disencumbered of the old, beset with half-involvements and half-detachments, nostalgic and sentimental on one level, an adept mimic or a secret outcast on another.

Consistent with Said's description of an exile, John expressed a strong desire to return to his community of origin, a feeling of being "so close and yet so far," and shifting feelings of attachment and detachment to both communities. From a disability studies perspective, it is important to remember that it was a lack of love, rights and solidarity for John, rather than his physical injuries, that was a major reason why he was placed in a nursing home. My first impressions of John's room in the nursing home, recorded in my journal, reflect some interesting observations about his social isolation:

> John's room only has one chair. So it's obvious that they don't expect him to have visitors . . . sometimes one of the other residents has a visitor who says hello to John, other than that he led me to believe I was the only visitor he'd had in four years. So his profound isolation is a central feature of his life. It's so different from my experiences, I have reservations about the extent to which I am really an insider with him. And yet, he told me that I was "the only other survivor" he'd met. That is a very inclusive statement. And he had prepared a list of questions to ask me, which he certainly wouldn't get to do with doctors. He asked me how old I was when I had my accident, how old

> I was now, how much money I received as my compensation payout, etc. I liked this because it indicated to me that he felt equally confident asking me questions as I did him. It was a mutual exchange, a sharing of information. So I feel there was some common ground between us.

Unlike some of the other participants, Rick has not faced social isolation. His friends and family, particularly his wife, have supported him ever since his accident. As he commented:

> Somehow when the seed of acceptance grows in the ground over life, it grows into some wonderful friendships.

It would be remiss if I concluded this discussion of social isolation without some acknowledgment of the role of impairment and the changed nature of relationships post-brain injury. When I watched the long-term social relationships of many of the people in the group, I noticed that there were certain characteristics of the impairment which may have contributed significantly to their social isolation. For instance, the anger management problems that many people experienced lead to enormous difficulties with relationships, even when partners were loving and devoted. It seems only fair to note that some loving family members made a difficult decision to discontinue contact with a family member who was liable to swear at them, abuse them, show no empathy towards them, or even be violent towards them. Likewise, the paranoid ideation that some people experienced as a result of their brain injuries meant that they became deeply suspicious of the people around them, and sometimes made false accusations about other people's behavior.

Inadequate Medical Care

As I noted in Chapter Two, diagnosis of brain injury is a difficult process which needs to be handled sensitively and carefully. It also suggested that ongoing rehabilitation was often necessary for survivors, as well as long-term support. However, many of the members of our group feel that the standard of care they received in hospital and in follow-up services has been inadequate. One of the consistent themes from the interviews with survivors was that the hospital system encouraged their families to have very low expectations of their lives after a head injury. For J, this attitude was symbolized in his placement in a "geriatric ward" at the hospital. The fact that he was not in age-appropriate surroundings or even impairment-appropriate surroundings suggested to him "you're written off." The fact that so much of his assessment emphasized what he could not do was very demoralizing for him:

> Not that I can't understand that I've had this injury, I understand it but it's pricks in society that won't let me get on with life because they keep judging me for what I can't do . . . Being where I am right now with the few problems, or many problems, if you focus on that you don't get anywhere at all . . . I'm alive, I'm trying to exist the best I can. Now I have to keep trying to reinvent things just trying to get by in this life. It's pretty hard sometimes . . . When I had my head injury I thought my life was put in the too hard basket . . . You cannot change their ways of operating or thinking to maybe improve the development of different ways of dealing with injuries . . . Frankly it sucks! They don't want to help you because—well I don't know why. I'm still kind of thinking about that. See you've got to work within their guidelines. Say yes please, thank you, bend over and I'll kiss your arse. The sort of thing when they want you, you know. You cannot offer them any constructive criticism because it's a system and they don't listen.

The "normalising" effects of the care system were also very important in the lives of members of the group. For instance, Larry suggested that one of the main themes in his rehabilitation was that he should try to hide his impairment and pretend that he was "normal." He still tries to do this:

> I have to put up a front. Can't let people know there's something wrong with me. I've always tried to hide it. I've learnt how to do that. I don't know how successful I've been in that pursuit. I just try to hide it, to think that I'm as normal as everyone else . . .

An element of the health care system which came in for criticism from group members was the grouping of a wide range of head injury survivors together, regardless of the severity of their impairments, as well as the arrangement of some areas in the hospital as "locked wards." Some individuals were frightened and confused by being placed in "locked wards." Kirsten said "It's depressing and I just thought just let me out, I'll do it myself." She emphasized the differences between her own state of health and some of those in the ward who were minimally responsive or who were still in a coma. "I thought, how am I supposed to progress in rehabilitation, rehabilitating when I've got to look at this?" She added that she was so demoralized by the time she was released from hospital, "I didn't give a stuff . . . I didn't care."

Reg stressed that the lack of follow-up and ongoing support was one of the worst elements of his experiences. "I was just dumped out (of the hospital) eighteen days later. And see ya!" He said that he needed such ongoing support:

> I had massive bouts of depression. I was suicidal . . . It's hard to be one person one day, have something happen to you, and the next day you're not.

He found that the lack of appropriate rehabilitation and support meant that he could not hold down a job. This meant his life became quite boring:

> If you're working, I found when I was working, I had something to do for ten hours of the day. I wasn't so lonely. Between working and going home five days a week time was just about taken up with daily living. When you're not working you're sitting around bored, you're watching TV so my best friend is the remote control. What I do most of my life I sit moving my fingers, playing with the remote control of my TV.

Steven also emphasized the poor quality of care which he received both at the hospital and subsequent to his discharge. He complained that he was left with soiled underwear for long periods of time in hospital and that the follow-up services were non-existent.

Helen stressed that although she did not receive any formal counseling or rehabilitation, her own determination to recover made this a positive thing:

> *Counselling—did you need, or did you receive any after your injury?*
>
> I don't know whether I needed it or not. I certainly wasn't offered it. I didn't receive it. In your confused state you would not think even of the possibility that it existed.
>
> *What about rehabilitation? Did you get rehabilitation?*
>
> No I wasn't given, well, only what I did myself. Which probably was better than what they would have given me anyway because I think I pushed myself tremendously hard. Even though that may be very stressful your brain relearns when you push yourself hard . . .

Helen believes that she pushed herself harder than any formal rehabilitation program would have, so not receiving any rehabilitation did not hinder her recovery.

Inappropriate and Inadequate Accommodation Options

Some of the people in our group had very severe brain injuries and their families were given very few accommodation options. For instance, John and Jill were placed in nursing homes and Madonna's family was also told that a nursing home would be the most appropriate accommodation for someone in her situation. At that stage, Madonna was only 18 years old. The fact that a nursing home would have been inappropriate is further evidenced by the fact that Madonna's family was able to rehabilitate her themselves, so that she was able to walk, talk, think, have relationships, and have an active social life. At the time, Madonna's family acted against the "doctors orders." Doctors suggested that she would never recover. They said she would remain "vegetative" forever.

Madonna's case is not unique. Being given a negative prediction about the future of a loved one is in fact a very common occurrence. Madonna's family was told that they should put her in a nursing home because she would never get any better. Thankfully, they didn't listen to this advice, and she now leads a rich and full life. I asked Madonna what life would have been like if she had been placed in the nursing home. She simply replied:

> Terrible . . . You wouldn't be able to do what you want to do, and go out and come back whatever time you want . . . Nursing homes, I've figured that nursing homes are for people who are elderly and are ready to die. They don't—like kids, don't like responsibility, so they put their parents in a nursing home. That's what I reckon it's for.

Similarly, John rues the day he was placed in a nursing home. He compares it to a jail that was very hard to escape. His meals were always the same, the music, activities and entertainment organized within the home were not aimed at people his age, and he watched three people die in his room. Eventually, he was moved to a single room, but the inappropriate accommodation has meant that he is very angry. One time he smashed his arm against the window in sheer desperation because of his anger about being written off and forgotten.

Some members of the group left hospital to return to their family homes. For instance Larry, who was twenty-two at the time, went to live with his father:

> Well when I came out of hospital I went and lived with my father . . . my parents had split up and he still had the house . . . When my Dad met somebody else I had to go . . . Then I went and lived with my mother for a little while. My money came through, so I bought myself a mobile home. I wanted to be independent and from there I met my ex, made me sell that bloody mobile home, which I should never have done. But I was, I also believe at that point I was easily talked into things. Easily led because I didn't know any better.
>
> *Because you're very vulnerable after you've had a brain injury, and people can take advantage of you quite easily.*

> People have, yes . . .
>
> *Are you happy where you're living now?*
>
> Yes, yes. I'm in a Housing Department unit, which is really good. I don't like being on the top floor but hey beggars can't be choosers.

It is interesting to reflect on Larry's housing situation. He is a public tenant of a State run housing organization and he is recognized as having a disability, yet he is expected to live on the top floor of a block of units. For someone with partial paralysis this seems completely inappropriate. Larry does not feel empowered to do anything about this inappropriate accommodation because, in his words, "beggars can't be choosers." His experiences with housing had led him to believe that he was not entitled to accessible accommodation as a right, and that he simply needed to adjust himself to this disabling environment.

Cliff has experienced significant housing problems since his stroke. His "challenging behavior" has led him to be evicted from many houses. For Cliff, trying to find suitable accommodation is intimately tied up with the search for social acceptance. He once said to me that he wished he could live in a group home, like those run by the Brain Injury Association, because he might not be rejected there. Personally, I was ambivalent about such a choice. I understood Cliff's desperate need for acceptance but I did not agree that segregated housing was the way to achieve it. He had been strongly influenced by the Brain Injury Association, which provides such segregated housing. He felt that the only way he could be understood was in an environment with other survivors and away from the rest of the community. I felt that such segregation did not offer the solutions he had hoped for. I also felt segregation was morally unacceptable. We had many discussions over this matter.

Accommodation barriers, like the ones identified in Larry's story, were only one of the difficulties experienced by many members of our group. Equally important was the disabling service system which many members of our group have found to be limited, patchy, and frequently unhelpful.

Disabling Services

Although services can be helpful and can make a difference in people's lives, some members of the group complained about their contact with the disability service system. Sometimes people had been rejected from services because brain injury was not considered within the ambit of "disability" as defined by the service. Larry reflected on this problem: "We are sort of discarded;

we're shoved under the bloody carpet; we're a non-person." In these cases people felt rejected, and sometimes lost the motivation to ask for support from any agency. A common response was "What's the point?"

On other occasions, people had visited agencies which specifically dealt with brain injury, such as the Commonwealth Rehabilitation Service (CRS), but they had mixed experiences with these services. One of the problems with these services is that they are structured in such a way that professional helpers exercise considerable power over survivors, who are defined as clients. There have been very few efforts to negotiate the delivery of services in a way which shares power with the people receiving those services.

Reg said that "The Commonwealth Rehabilitation Services, it's just a waste of time . . . They promise you everything and get your hopes up but they don't do anything." He said that signing up with the Commonwealth Rehabilitation Service "was the worst mistake I ever made." He said that they continually emphasized to him his lack of employability and his lack of work skills. This demoralized him for some time. Eventually they encouraged him to undertake voluntary work, but this did not lead to paid employment. Subsequently he enrolled to do an Associate Diploma in Computer Information in order to get the skills to find a better job:

> But even after I did that they couldn't get me a job. First up you aren't qualified, you've got no skills. Okay so I went in and got qualified and got skills and they still can't do anything.

Reg found no help from the Brain Injury Association either. He said that:

> When I first started going to their meetings they had some support for us. Now you go there and you feel like an arsehole. There's no point. It makes you feel worse.

Similarly, Madonna said her experiences with the Commonwealth Rehabilitation Service were "terrible." She had been encouraged to do voluntary work but "I said that if I'm not going to get paid I'm not working." Larry had visited the same agency and said they were "shit . . . fucking morons." When I asked Larry to explain in more detail what he meant, he said:

> CRS are useless pricks! All they did—I went to CRS for a little while—all they did was put me through exercises. And I just thought to myself, what is this crap? I've done all this. What am I doing? They're supposed

> to help me get into some employment. They never did anything like that at all, just like oh do this exercise, do this exercise. I just told them to go jump and got out of there. I didn't bother with it. The CES, now Centrelink, is just as frickin' useless. They never helped because either . . . They couldn't give a toss, just sit you in the back; just sit there. Don't worry about him! See he hasn't got a chance of getting any employment. They're morons too.

Some members of the group were very happy with their experiences at these agencies. J said that his experience with one of the workers at CRS was wonderful:

> I met a wonderful social worker who wanted to help me achieve what I wanted to do. One of those goals was to learn to drive. She made that happen for me. She was fantastic . . .
>
> *What made her so good? What can we learn from what she did?*
>
> Because she was a woman who wanted to try and help me get to where I wanted to go. . . . She had the system behind her. She was willing to try and let me achieve my goals, see how far I could push it.
>
> *So she believed in you?*
>
> Yeah, she's a beautiful woman. I mean don't take that the wrong way. She's a beautiful woman in her heart, and I wish more people like her. She was middle aged or thereabouts. She couldn't do enough to accommodate my needs, and wishing to try and help me get somewhere. Because of her hand, her caring, her generosity, you know, I doubt whether I would have got as far as I want. And I have without her. The reason why, what makes her so different from most other people, she would listen and what's the word, compassionate. She was a beautiful, beautiful woman who cared about my state of mind.

Kirsten has found the Acquired Brain Injury Outreach Service (ABIOS) a very useful source of support and rehabilitation assistance. In fact, she thinks they are "unreal." She has also had positive experiences with the CRS:

> Well what happened with me, the reason why I got them was because after I got out of hospital well then apparently I had to go up once a week to Rehab. So I went up one week, made a real arse out of myself, they kicked me out. What they've done is they've put me on the ABI list for people to come around to your house. I remember thinking okay give this sheila a go. If she pisses me off I'll tell her. Anyway we just became such good mates it wasn't funny. Then the new one after that, the same thing. She only got rid of me about a month ago.
>
> *So they're finished with you now?*

> Providing I, you know, if I need it I'd ring. It's not a problem. But yes, they were unreal.
>
> *What do they do for you?*
>
> Well they used to come around talk, just talk, and of course at that stage I was still real mixed up and they'd sort of sort it out for you . . . And then if you need, if you needed anything. It could be help somewhere else, they'd get it for you. And you know, so they were unreal. They were support. I could ring anytime I needed. I even got friends with the receptionist. I mean we're mates. She knew my voice straight away. They were very supportive. But now when I haven't got them I do feel a little bit lost. I've never done anything by myself since the accident. Never. Now I've got CRS so I sort of bail them up every now and again. They're another good lot.
>
> *So you like CRS?*
>
> Love 'em! . . . They accept me now as who I am. I don't have to pretend I'm someone else.

The Brain Injury Association of Queensland (BIAQ) is the major organization funded by Disability Services Queensland to assist people with a brain injury. However, it is a service provider—it provides group homes, a telephone service, some individual counseling and intermittently, group work. The conflicts between its role as a service provider and the need for independent advocacy are one of the main reasons why we set up a group which was independent from the Brain Injury Association of Queensland. Also, some people in our group felt that they weren't being treated appropriately at the BIAQ. For instance, Madonna felt that they have changed over time and become less respectful:

> Now that they've changed, people . . . they still treat everybody like they're imbeciles. . . . But see, if you speak up for yourself, then they think you're crazy . . . So that's why I just, if anybody says anything, that's why I just keep my mouth shut. Because if you go to say something, they automatically think 'she's crazy.' Or if they know that you've had a head injury—see a head injury not brain—you had a head injury. They know that you've had one, they presume, 'oh it's because of the brain injury she's had.' See if they know that.
>
> *They use that to blame everything?*
>
> Yeah. And they can't.

On another occasion Madonna said to me that she did not care how bad the Brain Injury Association was because it was not important in her life. What was important in her life was the relationship she had with her boyfriend and the friendships she had with other people who had brain injuries: "Well it doesn't matter because we've got each other. We are friends."

Duncan indicated that he is very unhappy with the BIAQ. He went there to ask someone to visit his wife, to try to help get rehabilitation for her, and to find out information about the latest treatments for someone in her condition. They refused to visit his wife, gave him information that was ten years out of date, and then asked him to come to a counseling session where he was encouraged to cry and let his emotions out:

> These jokers don't realise how much harm they do by not helping people but they're playing on their emotions with stupid word play. They don't know. They're professional people in a sense. They've gone to university or college or whatever, they've got a certificate but they haven't worked with the actual medium of brain injured people. They wouldn't know how to give them a glass of water if they're just out of a trachy. They wouldn't know how to communicate with them. They wouldn't know where to write. They wouldn't know what state they're in. They would not know anything. So I think it's a bit like a mechanic, he knows all about the car. These guys are just salespeople and unfortunately that's what we're hitting, we're hitting salespeople. And again that's a frustration until you meet someone who can tell you a little bit more about it and guide you in a brighter light. Because these guys are really puppets in my opinion.

Reg agreed with the criticisms made by Madonna and Duncan: "The Brain Injury Association is not even worth looking at, it's pathetic."

J stresses that organizations which are dominated by professionals, like the Brain Injury Association, offer little real assistance to survivors, because they don't understand what people have experienced:

> Because—sorry—a textbook reader wouldn't know diddly-squat about what a head injured or any person with a disability. They don't have that information. None of the textbooks can tell you, you have to live with it, alright. So I mean all the professionals can go and get screwed.

Some of the members of the group are less critical of the BIAQ. For instance, Larry states that in the past, the Association was very helpful to him. So it seems that a minority of the people in our group had positive experiences with the service system, although the majority were not happy. Of course, some of the research participants had no complaints because they had no contact with the disability service system. For instance, I asked Helen "So have you ever received any disability services?" and she simply replied "No, not one!."

Another major disabling barrier identified by research participants was difficulty in trying to find work. Employment barriers prevented many people from achieving their goals in life.

Employment Barriers

The majority of the people in the group were not working and faced significant barriers when trying to find work. J said that he dreams of having "a life" and a job, and leaving the stigma of being an unemployed disabled person:

> Yeah a life would be nice. I want to be able to, to make a living, make my own money so I can tell the government they can dump their stinking pension. I want to improve for myself my worth and my expecting child. All improvements help. Feel more whole, a person. Even though I shouldn't feel less of a person, society makes you feel that way when you don't or you cannot physically contribute. They make you feel less of a person.

Larry is also out of the workforce and said that he would like to have a job which suited his abilities:

> I'd like to work, work at something I'm capable of doing, that wouldn't tax me as in physically, a lot. So I wouldn't be dead at the end of the day. I'd like to do it but as I said, something I'm capable of doing.

Larry also said that he had experienced a lot of discrimination when he had applied for jobs:

> Especially going for jobs, going for work . . . And once the potential employers found out that I had an injury and that I had special needs, they didn't want to know you. They'd just say oh yeah we'll get in contact with you and they never bloody did. You got very disillusioned about that.

When Larry had found work, he was often pressured to work faster than he could safely cope:

> Every time I started a new job, they'd want you to go quick. They wanted you to go fast. And sadly I couldn't do that because of my injury. I had to go slow because I had to be sure of all the dangers

> involved. That's why I've lost the tip of my finger. I've had my finger cut way open, my leg, scars all over me, here there and everywhere. Because they wanted me to have a quota. They wanted me to be quick at the job. And every time I'd quicken myself up I'd forget the safety stuff and I'd forget—oh have I put that on? Is that right? I'd check it and unfortunately when I do check it it's too late and I've got my finger caught up. I've got it sliced. It's not good.

Like many disabled people, Larry faced not only unemployment but also under-employment. That is, his employment was on the margins of the labor force in unskilled jobs which were quite risky physically and which did not pay well. Through listening to Larry's story, it is possible to gain an insight into the vulnerability of some brain-injury survivors. He has gained a further impairment through his experiences in the workforce. The loss of a section of his finger is a reflection of the pressure he felt to speed up his work rate. Safety at work seems to be difficult to negotiate for people on the margins of the labor force.

Like Larry, Reg also experienced a considerable period of unemployment following his injury. For the first two years after his accident, he was not able to work: "I wasn't capable of working for two years afterwards. Even after I became mentally capable, I wasn't physically capable like I used to be before the accident." Eventually when he recovered enough to return to the workforce, he too faced employment in sectors which were relatively low-paying and which had no job security. Reg also reports abuse at work associated with one dreadful employment experience: "My boss hit me with his car . . . I was the last one in the queue for the lunch truck. Everybody was walking at the lunch truck, although there were fifteen people there at the lunch truck, he's hit me from behind." Reg reported many conflicts with work colleagues. He can easily become aggressive and needs a supportive work environment, but he has never had this opportunity. Life at the margins of the labor force is hardly a supportive environment.

Madonna is also not working. She thought that she might be too slow for some jobs, and might not have the experience for others, but felt that if she worked she wanted a decent pay. She was mindful of the fact that she would lose half her pension if she worked. She was not interested in doing voluntary work, because she felt that if she was in the workforce, she wanted a real job and real pay:

> No I'm not employed.
>
> *Would you like to be?*

> Yes and no. Yes I'd like to work but I wouldn't because I wouldn't be quick enough or anything like that. And I wouldn't be experienced like how they've got in the paper you've got to have two years experience for doing something.
>
> *But there are some things that you could do that you'd be very good at.*
>
> Yeah but I don't want to do any volunteering work. I don't want to do that.
>
> *If you get a job you want a real job where it pays.*
>
> Yeah.
>
> *Because that's what people work for.*
>
> Yeah but see, if you do that then, well if I do that then they reduce your pension.

Like Madonna, most of the people in our group live on the disability pension. This means they live in poverty. They are often worried that finding work will mean their pension is reduced, as Larry commented:

> See if you try and work you're screwed because you lose much of that disability allowance. Because I'm in Housing Department, your rent goes up to market value. So basically you're exactly where you started from. There's no benefit, there's just no benefit. Though you do get it weekly, you're so far behind on other things because you've been on the pension that you've got to pay off those things and you don't have any money left for yourself again.

Nevertheless, many of the participants dream that one day, they will find work in a suitable and supportive environment, and hope that having a job means they will have more options in life. However, they tend to report experiences of negative and discriminatory attitudes among employers and the general public which has denied them employment opportunities. This discrimination is not only psychologically hurtful but has long-term economic implications as well. There is a strong link between disability and poverty.

Although John lived in a nursing home when I first met him, with appropriate supports he could possibly have managed some part time work. He has a likeable personality and many skills that could be useful in a job. However, no-one has ever spoken to John about this possibility. Now that he is living in the community he still has not received any supports which would facilitate participation in the labor market. Deficiencies in the disability service system and discriminatory attitudes from other people have denied him a chance to find a job. This is particularly disturbing when one considers that many of the social and economic rights associated with citizenship depend on having a job and a decent income.

Rick is in an unusual position because he was self-employed at the time of his accident and he was covered by insurance through an Income Protection Plan. This has meant that he has maintained his income despite being out of the workforce. Unlike other members of the group, he has been able to purchase his own house, and has not experienced any accommodation barriers. It seems that Rick's advantageous financial position prior to his accident has meant that he has faced fewer disabling barriers than others.

Lack of Technical Aids and Equipment

Technical aids can make a great difference to the life of a person with a disability. For instance, a closed circuit television can make it much easier for a person with a vision impairment to access print materials. A hearing aid may also make life easier for a person with a hearing impairment. Wheelchairs can make mobility a lot easier for people who might otherwise struggle to get around. Similarly, incontinence pads can be very useful for people who have bowel or bladder control issues. However, one of the most noticeable effects of the exclusion of brain injury survivors from the disability support system is that they are rarely provided with such technical aids. For instance, Reg has both a vision impairment and a hearing impairment but he is expected to cope without any assistive equipment. Likewise, many members of the group struggle with balance and find walking very difficult but only two of the twelve members have disability parking permits. It is generally assumed by members of the group that they are ineligible for such supports because their main impairment, brain injury, is invisible, and they are routinely denied access to disability services. The lack of funding for technical aids and equipment is morally reprehensible. For instance, Jill waited for over two years before she was provided with a wheelchair. For those two years she was bedridden. Such blatant disregard for the rights of brain injury survivors is a human rights travesty.

Another major unmet need among brain injury survivors is for appropriate psychological and psychiatric support, often on an ongoing basis. Cliff's experiences in psychiatric institutions (which seem to have a revolving door policy) are one glaring example of a systemic failure to provide support to brain injury survivors. However he is not alone. Despite having years of contact with the psychiatric system, John stopped receiving such services when he acquired his brain injury. Just at the time when such services would have been most useful, they were withdrawn.

Jill has also borne the brunt of the inadequacies of the service system. When she was due to be released from the nursing home, she was not supplied with any incontinence pads nor with any intravenous food solutions. Accordingly, her husband had to purchase these necessities before she could come home. She was incarcerated in the nursing home for an additional weekend while he arranged these supplies. He was not provided with any advice regarding where to purchase these supplies—once she had been discharged, that was considered a "private matter." Again, he was not provided with any directions about how to change dressings or give injections or even how to change the intravenous drip. He went over two years without even one weekend of respite. Jill's unpaid informal helpers in the form of her family had taken over responsibility when the State had failed its civic obligations towards her.

Transport Barriers

Many of the members of our group cannot drive. This means that they are reliant on public transport. Transport systems which are not accessible are therefore a significant barrier in terms of education, recreation and employment opportunities. Madonna said that she had always dreamed of buying a car with her compensation pay out. "I always said the first thing I'd buy is a Ferrari." However she cannot drive as a result of her coordination problems and negotiating the inaccessible public transport system presents major challenges for her.

Poverty is a major reason why some members of our group do not own a car. For instance, Reg has a driver's license but cannot afford to buy a car. He is therefore reliant on public transport. This public transport system is inadequate in the area that he lives—one hour from the centre of the city. Buses are irregular and there is no train access. His reliance on public transport also reduces Reg's competitiveness in the labor market.

There are a number of people in our group who cannot drive because of the cognitive or physical changes associated with their brain injury. For instance, both Steven and Cliff have epilepsy and are therefore unable to hold a driver's license. Also, both Rick and Madonna have significant balance and coordination problems which prevent them from driving. Only Madonna has been able to receive discount travel vouchers which allow her discounts on taxi fares. The others do not receive such concessions. They utilize taxis and the public transport system a great deal, but receive no assistance in doing so.

Abuse

Abuse has been an issue which has continually been raised in BIAG meetings, particularly by women, people from Non-English Speaking and Aboriginal

Backgrounds, and people who have dual impairments (such as a brain injury and a psychiatric impairment). It seems, anecdotally, that abuse is a common experience, particularly for women. Comments from one participant highlighted the importance to me of gender and racial identities. This woman was from a Non-English Speaking Background, and her identities as a woman and as a person from a minority culture are quite central to her experiences. While she does not identify many of these experiences as racism or sexism, my journal notes about her were full of references to her experiences of domestic violence and racism. My notes reflect continually seeing her experiencing emotional abuse, as well as a persistent fear of physical abuse, and seeing her often cry and say that she was depressed. Her partner's domestic violence was intimately tied up with controlling behavior. He was monitoring everything she did. One of my field notes illustrates this point very well. It contained references to their names, so I have taken those names out and replaced it with two symbols—person "X" and person "Y":

> X and I had lunch in the city. We both had a voucher for a half-price meal at a fancy restaurant, and so we decided to splurge and have a meal there. Y rang three times while we were still waiting for the entrees. He was jealous. Y told X that he would be getting a friend who works nearby to check up on us, to prove we weren't having a clandestine affair. Y knows that I am a very happily married man. He has been in our house and seen me with my wife. He has heard me talk of my love for my wife, and how I feel she gave me hope when I had none. Y had seen me with other people too, and I find it incredible that he hadn't noticed that I set very clear boundaries that distinguish between friendship and romance. Maybe he didn't notice that. But he still knew that X and I were both in committed relationships and were just friends. Y knows that X tells everyone that she loves him. She often says she wants to move in with him, and marry him. Nevertheless, he couldn't overcome his jealousy. He rang about six times in the hour. He seemed to have this warped idea, as if we were having sex in the restaurant or something.

My field notes also record that she was very upset after experiences of emotional abuse:

> She said she loved him and I asked her, "When does he make you happy? I only see you upset by him." She said the abuse was bad, "but it stops when I cry." She said he is nicer to her after he makes her cry.

I heard many stories of her partner being involved in physical fights, but she never spoke of him hitting her. I did see him once point at her threateningly, sticking his finger in the middle of her face and saying, “shut up.” She had a very scared look on her face which made me suspect that he had been violent towards her. On another occasion, my field notes record her mother ringing me and complaining about the domestic violence she was experiencing herself. I record my feeling that it is “almost a pattern of inherited domestic violence.” My notes also record the racism which was omnipresent in the life of this brain injury survivor. Even in her most intimate relationship with her boyfriend, she was referred to as a “wog.” I heard such references in both public and private discussions, not just by the partner but also from other brain injury survivors towards her. Other parts of my field notes record conversations we had around escaping from domestic violence:

> (She) tells me that she is scared that if she breaks up with (him), she will never meet someone as good as him again. I tell her that he isn’t such a great catch anyway, and that she needs to be happy with or without a man in her life.

This woman was not the only research participant who experienced abuse or domestic violence. Another member of the group also reported experiences of abuse in a relationship:

> I went back and lived with my former partner yeah, yeah. And he was tremendously unsympathetic. And also, because he didn’t feel like being communicative, he’d just then neglect to tell me things and then say oh no I told you, you just can’t remember anything anymore.
>
> *Yes, so there’s a real tendency to blame everything on the one with the head-knock, don’t you get that?*
>
> Yes there was, and the interesting thing was of course that I didn’t have difficulty remembering if someone told me. What you have difficulty doing is bringing it back up to the surface and getting those details clearly in front of your eyes, you know what I mean. They, not having it, don’t know the difference and they don’t know that you know very well when they’re lying to you . . . it really was quite cruel the way that I felt that he was treating me.

Another participant in the study reflected on the ways in which his intimate relationships also changed as a result of his accident:

> Yeah my ex-wife, she used and abused me. Emotionally and mentally. She mentally abused me like she’d call me names and all that sort of shit.

> *Like what names did she call you?*
>
> Oh. What did she used to call me? Jesus, it was a long time ago now. I guess it was 'you're stupid,' 'you forget stuff,' 'you're an idiot,' which were hurtful, especially coming from your wife. It's not good.

He also said that he had been financially abused in the relationship and that people with a head injury are very vulnerable and can easily be exploited and abused:

> Like my ex, she, I don't know whether she abused me, but exploited me. Because for a long while there, she didn't know I had any money. And then when she found out, instead of having eyes she had dollar signs. And I think she got that from her mother unfortunately. That was the end of that! I mean she married me, she said well I don't need you no more, I've got your money, all I've got to do is divorce you. So that's what she did. That's not a problem.

Restrictive Notions of Disabled Sexuality

One participant discussed at length the importance of her identity as lesbian to her, and the ways in which she had felt pressured to conceal that identity. Despite many professional interventions regarding both her experience of disability and impairment, no professionals had ever offered any support in this area:

> I have so many issues of my own, that I really can't share with anyone . . . And well you know it's a big deal to me but . . . Other stuff that I am trying to go through but is—oh how can I put it? Well all I can say is it's not really sociably acceptable. Right?

I sensed that she was talking about "coming out" as a lesbian. Although she had not formally come out in our group, her sexual orientation was widely known. I indicated to her that a process of "coming out" is often very tough:

> Oh-hoh! No one knows how tough! . . . I can't. I do, sometimes, I just want to run away . . .

This participant stressed that other people's limited views of her lifestyle options were denying her the right to freely express her sexuality. Decisions about entering into a relationship had become much more difficult for her:

> Yep, and you feel like you really can't make them because you're not supposed to, and well that's not me. I love my girls. I don't think anyone gets it. I mean my Mum's still going on, "When are you getting a boyfriend?" . . . The thing is, because people don't talk about sexuality, everything gets swept under the carpet . . . It's just don't talk about anything that's different because you need to sweep it under the carpet . . . 'You're not supposed to do that'—it's a load of crap. It's the same thing where you're not meant to have a brain injury. Same thing, sweep it. And I mean I've, look I've always known my whole life okay, but after the brain injury in the rehab. It just confirmed it. I didn't need it. Okay you can't shut it up anymore like I was doing—shutting it up.

I suggested to her that it is much harder to keep secrets after a brain injury, particularly a frontal lobe injury which makes you more disinhibited. She agreed that it was much harder to establish the pretence that she was "straight":

> Well I was. I thought I can't keep doing this, keeping it quiet, I can't. So I'm dealing all the time with stuff like that and I'm thinking I wish it'd just go away. I mean it's not like you know this was deliberate.
>
> *Of course not, it's who you are. You can't pick your sexuality.*
>
> Do you know what I mean? So I'm trying to deal with all that . . .

I responded by discussing some of the stories of my friends who had "come out," and the processes they went through in telling their families. I then asked her about whether she had thought of "coming out" to her family. She replied that she had sensed that their reaction would be very hostile: "Maybe I'm totally wrong but I don't want to take the risk. I can't."

Another participant, John, also stressed that restrictive notions of sexuality had prevented him from having an active sex life. When he was in a nursing home, he expressed a desire to have sex. A few informal discussions were held with nursing staff about arranging a sex worker to visit him. However, the nurses decided that they felt uncomfortable about this and John remained celibate for 8 years.

CONCLUSION

This chapter has suggested that disabling barriers play a major role in the lives of the participants in this study, preventing them from having equal opportunities in a wide range of areas including employment, education, income, and relationships. The social model of disability, discussed in Chapter Three, suggests that such barriers represent a significant diminution of human rights. The fact that some of the services which are supposed to uphold and improve the rights of brain injury survivors may actually play a major role in creating their oppression is particularly worrying. The chapter has therefore identified a number of areas (such as service delivery, transport barriers and so on) which urgently need to be reformed. The existence of so many disabling barriers in the lives of brain injury survivors should therefore be a major concern to anyone who has a commitment to social justice.

While the social and medical models are clearly relevant to some of the experiences of participants in this study, they do not sufficiently address the questions of identity and embodiment which have been emphasized by participants. The following chapter will consider such issues, even though they are not reflected in the literature on the social model or the medical model, because they offer additional insights into the lives of the people who have participated in this research.

Chapter Seven
Differend Perspectives

INTRODUCTION

This chapter takes its title from a book by Lyotard (1988: 9) which uses the term "differend" perspectives to discuss the way discursive frameworks may exclude or silence some needs and interests. It has been a consistent argument throughout this book that certain interests are excluded when a binary disabled/nondisabled dichotomy is developed. In particular, such an approach fails to recognize the complexities of disability identity. It also leads to a vanguardist approach which dismisses denial of disability identity by an impaired person as "false consciousness." Such an approach is theoretically flawed and practically unsatisfactory. It needs to be accepted that there are many impaired people who refuse to identify as disabled. As a result, there is a need to grapple with the complexities of disability and impairment identities in detail. This chapter seeks to rise to this challenge. It positions a number of participants along a continuum of disability and impairment identities, including hybrid and ambivalent identities. It also engages with the question of how to incorporate the experience of embodiment into the understanding of brain injury. The earlier chapters in this book suggested that there had also been a structured silence around the issue of embodiment. Brain injury survivors often experience fundamental changes in mind and body and they may have a "differend" perspective on the topic as well. Finally, the chapter draws on Michel Foucault's conception of "productive power" and to a lesser extent, Judith Butler's (1997) notion of "subjection," in order to demonstrate that power is not simply a negative phenomenon which oppresses (as the social model assumes) but also invests people with strength. Instead of the image of brain injury survivors as the victims of an impairment (as the medical model suggests) or the victims of disabling barriers (as the social model suggests), the chapter concludes by highlighting the resistance and agency of the people in this study.

THE COMPLEXITIES OF DISABILITY AND IMPAIRMENT IDENTITIES

One of the most interesting aspects of this study has been discussion around the topic of identity. In disability studies, the focus of such a discussion tends to be on whether people with a particular impairment define themselves as disabled. In this regard, the participants in this study have a number of interesting points to make. Some group members clearly and consistently identify as disabled and locate disabling barriers in the social and physical environment as major barriers to their lives. Others do not identify as disabled at all. They identify as having a brain injury (these individuals do not deny they have an impairment), but they do not articulate any connection between that experience and the experience of "disability." They associate disability with physical, intellectual or sensory impairments and since brain injury does not fit easily into any of these categories, they believe that they are not disabled. Others are less aware of any ongoing effects of their brain injuries and therefore deny that they are either impaired or disabled. When issues associated with their brain injury cause them problems, these individuals try to hide their impairment and hope that it will remain invisible and un-noticed. Still others identify as disabled, or impaired, only in certain circumstances.

Indeed, a continuum of disability and impairment identities seems to exist within the group. People place themselves along this continuum in different ways at different times, so an individual might locate themselves on the right of the diagram in one situation and one the left another. The postcolonial concepts of ambivalence and hybridity (used extensively in the work of Homi Bhabha, 1990, 1994) are particularly useful in this discussion. These concepts suggest that rather than finding an undiluted, "authentic" voice of opposition among marginalized groups, it is far more common to uncover both resistance and complicity. In this vein, it seems that disability studies could benefit from identifying a fluid continuum of subject positions with regard to impairment and disability identities. One such continuum is presented below, in Table 7.1.

Of course, these impairment/disability identities overlap with other identities in people's lives: at other times they identify in alternate subject positions, such as on the basis of their sex, gender, ethnicity, sexual preference, and so on. But here, the focus is on their identities in terms of disability

Table7.1. A Continuum of Disability/Impairment Identities

High identification with the Social Model			Low identification with the Social Model
Consistently identifies both as Disabled and Impaired	Sometimes identifies both as Disabled and Impaired	Identifies either as: Disabled (not Impaired); or Impaired (not Disabled)	Identifies as neither Disabled nor Impaired.

and impairment, in order to show that the situation is much more complicated than some versions of the social model suggest.

I will now discuss some of the identities adopted by members of people in this study. I think it would be useful to begin by discussing the disability identity of "J." His approach to disability is very consistent with the social model. He identifies as both impaired and disabled. J said that when he was injured, he really wanted to get a drivers licensee. Other people did not have faith in him and discouraged him from trying to get a licensee. With adaptive equipment (a car knob) he was able to drive and pass his driver's test. Nevertheless, he still feels that when people notice the adaptive technology in his car, he is watched and devalued:

> Well, all I wanted to achieve was to get a licence to drive, but I can't. And everyone told me, don't achieve so high, for my goals. But I shot for them anyway. I (now) have my drivers licence. Ever since I've got that licence I would have thought I would've been treated so much better by people because I achieved to get my licence with the troubles that I have. I follow road rules and all that. I'm made to because I'm different. I'm watched. I'm watched a lot more closer than every other people that gets their licence out of the Weetbix pack, and abuses the privilege time and time again. And like I just . . . all I keep getting is hassles from people because I don't fit in.
>
> After the injury, we discontinue as far as a normal life . . . No one wants to help. And I'm not just saying this. I'm written off and that's the way it is. No one wants to help you . . .
>
> We don't have any money. The little bit of money we do get is not nearly enough to survive on. And they expect us to be able to save. They expect us to be able to go out and enjoy ourselves. Well that to

> me is not—I mean life's not only the money, it's attitudes. Attitudes that you, society, have about anyone different. And until that changes, not much will improve . . . It's about anyone different. Anyone who doesn't fit into the category of 'normal.' Whether you're black, white, female or male, gay, lesbian, there's too much discrimination . . . They expect us to live on peanuts. They don't provide us with any opportunities. We're just a write-off . . . I mean, like, I know myself I've reached the stage where I just couldn't be bothered to try and get out and have fun because it's always thrown up in your face. Why try because everyone stares at you because you're different or the way you dress because you haven't got any money. And it's a spiral. You just can't get off it . . . I know it's not fair, but that's the way it is mate. It's the way it is.

The social model approach adequately interprets experiences like those which J described. It notes his impairment and the need for adaptive technology and emphasizes how he is oppressed by negative public reactions. J's experience of being stared at and watched closely because he looks "different" is consistent with the emphasis of the social model on the way disabled people are continually oppressed in social situations. Likewise, his lack of money is explained by the social model as a part of the systemic exclusion of disabled people from the labor force.

J rejects the idea that you can say you are either "better" or "worse" after an injury:

> Well I mean, who's to say whether you're a worse or a better person for an injury? I mean, I don't know anyone named God, that can judge or has a right to judge. Gee there are a lot of human beings who want to play God. I've got a question to every able-bodied person. What gives you the right to judge what or what we cannot do or try to do? Why keep us down when we're willing to put the effort in? We have to work a lot harder than most people to get on an equal par to an able-bodied person. So, I mean, what gives you the right to knock us down? And if you give us a go you might be pleasantly surprised.

In this narrative, J contests the conflation of disability with inferiority. His comments would be generally consistent with that of a social model theorist. However, on some emotional levels, his analysis is not so clear-cut. I sensed that J felt a deep-seated ambivalence about identifying as disabled. This came out when he contrasted his life before and after the brain injury and for me, was summed up in his later comment "I try not to talk about things in my past life because the old J is dead."

Unlike J, who has lived with a constant sense of his impairment all his adult life, Steven's impairment identity has recently changed. He has only recently come to identify as a brain injury survivor. Previously, he identified as someone who had epilepsy:

> Now it's only been recent times that I've come to consider that I've had brain damage as such, I've looked upon it as just being epilepsy I've had.

Steven sees that identifying as a brain injury survivor helps other people to understand why he has epilepsy. His experience shows the fluid nature of impairment identities—for years he identified in one way and his self image was caught up with that identification. However, when he recently was diagnosed as having a brain injury, he found the diagnosis liberating because he could understand why he experienced seizures. His impairment identity has changed as a result.

Some of the members of the group identified as having a brain injury but not being "disabled." The identities of "brain injury survivor" and "disabled person" were quite distinct for them. They define someone as "disabled" if they have an intellectual, sensory or physical impairment, but they did not perceive themselves in this way. Their problems are the result of brain injury, which they felt does not neatly fit into the category of "disability." Rejection from disability services on the grounds that ABI was not one of the "disabilities" which they serviced reinforced this idea among some participants.

Another element which seems important to some people is the fact that brain injury is invisible. One of the reasons why Rick does not identify as disabled is because he feels that his brain injury is invisible so people are unaware of it when they meet him. He sees "disability" as a category that implies visible bodily differences. Also, he does not view the changes in himself as permanent and he regards disability as a permanent individual trait. Finally, he conceives of disability solely in negative terms, and that is not how he wants to view himself. I began one of our interviews by asking him "You don't identify yourself as disabled do you?" He replied:

> No.
>
> *Why is that?*
>
> Because I see myself as a restored man.

When I probed to find out more about what he meant, he began with some general reflections on life "Life's not static in my mind. It's open-ended, expanding." He added that his problems were really only "minor in relation to the world." He added that he understood the word "disabled" to mean "Many barriers in place. For me there are very few barriers." He said that "I can do lots of other things now . . . but I think as I look at other brain injured people, they seem to be very limited in what they can do." He also wanted to emphasize that disability was a negative experience, but his experience was a positive one. He had moved from what he called an "unsustainable life" to one which was much more balanced and happy. Another important element in his understanding of disability was the sense that it had to be visible to other people:

> If you're in a wheelchair and you get up and started walking, sure you can see it. But people don't see the progression of brain improving over the months, do they? They just think we're normal.
>
> *Do you have a disabled sticker to your car?*
>
> No, no.
>
> *Even though you have mobility problems?*
>
> No, because I don't see myself as disabled! No I don't see that. I don't see myself as disabled. I see myself as being a recycled man. I had a brain injury but I see that it's in the past. I don't see it as going to affect me in the future. In fact I think it's one of the best things I've had . . . Yeah, I'm about to break into new time. I see my life as past, middle and future. I see that as a good thing . . .
>
> *An interesting thing that you said was you don't identify with being disabled. What's wrong with identifying with disabled people?*
>
> I don't see myself as having . . . I see I have some difficulties but they're not permanent. Therefore I don't see myself as disabled. I think someone who sees themself as disabled, they see themself in a negative way. I don't think in terms of loss, I think in terms of gain.
>
> *Okay so do you conceive of disability as a purely negative experience?*
>
> Yep.
>
> *Has anyone ever talked to you about disability as being good for you? Has anyone ever talked about, have you ever heard anyone talk about, disability pride?*
>
> No. I could do it though. I'm not down on the people who are disabled at all. But for me personally, I see myself growing into something new. Does that fit?

Rick expressed to me that he had learned a lot about disability from his work with me in the brain injury survivors group. His attitudes towards disability had changed, he said. This was a common experience for people who acquired their impairments as adults.

Larry, another member of the group, is an active member of many disability organizations including the "Sporting Wheelies." He receives the Disability Pension. However, he does not personally identify as "disabled." He identifies as a "brain injury survivor" which has a quite distinct meaning for him. He sees disability as a form of physical difference in the body, and his problem is not in the body but in the brain. He says "I'm an able-bodied. Sorry, I can walk pretty well without assistance."

Participants like Larry and Rick have contested the definition of "disability" by trying to develop a positive image of themselves despite living in a disabling world. "You can either see it as half full or half-empty. We see it as half-full," said Rick. The group has assisted both of these men to assert the value of an identity as a "brain injury survivor." Larry summed this feeling up quite clearly:

> Well there is one good thing about it, is that you all know you're in the same boat. We don't have to, because we know what everyone's like—as I said we're all in the same boat—we don't have to explain ourselves to one another. We don't have to explain to why we're like the way we are, because we know why that's the way we are. And with the circle of friends, it's good for everyone because it gives us good self esteem, and we go and do something instead of sitting at home being bored to death . . . I'm glad I'm a survivor!

Nevertheless, Larry does not define himself as disabled and his refusal to accept the disabled identity has caused him some emotional difficulties. For instance, he was attending a Rehabilitation Clinic for disabled people but stopped attending because he felt that he did not deserve to take the place of a disabled person who was needier:

> Because I felt that there was people there who needed more help than I. Because everyday there was just people that were worse off than I was. And I felt why are they looking after me when there are people out there who need more help than me? So I went there for two weeks, and I still don't think it was purposeful for me. So I don't think I got anything out of it. Though they did do a lot of co-ordination stuff which was, although the hospital did anyway. Not really much more than that. I didn't feel that I needed it. But I think I was wrong because they were giving me the help that I think they should have. Knowing that now, not knowing that then.

Larry could not see that someone who needed cognitive rehabilitation deserved an opportunity to attend a rehabilitation centre just as much as someone with a physical or sensory impairment. He left the program, voluntarily.

Unlike Rick and Larry, who clearly recognize that they have brain injuries but do not define themselves as disabled, Madonna is ambivalent about whether she is either disabled or impaired. She receives the Disability Pension as the result of her accident, but she feels that her symptoms are not consistent with what she understands to be brain injury. Her identity is strongly influenced by her own understanding of brain injury and her extended period of unconsciousness.

> I didn't know I had a brain injury. Yeah because the hospital people claim that, yeah, you have a brain injury, if you can't remember what happened, like how you had your accident. Well then you could blame that on your brain injury. But if you can remember what happened and how it happened and where it happened . . . I don't think they knew I had a brain injury. I don't feel like I've got one either.

Madonna feels that because she can remember her injury, and she believes that people with a brain injury cannot remember their injuries, then by definition, she cannot be brain injured. So she neither identifies as brain injured, nor impaired, nor disabled. She struggles to negotiate this "non-impaired, non-disabled" identity in the face of many hurdles. She knows that her memory is poor on occasion, but she is aware of how much better it is now than it was straight after her accident. She doesn't think that she has memory problems, and she thinks that all people with a brain injury have memory problems. Similarly, her balance isn't as good as it was prior to her accident, but it is much better than it was in the period immediately after her accident. She thinks that judgments about balance are all relative, and she feels so much better now than she did years ago when she first had her injury. So Madonna genuinely thinks that she is no longer brain injured, no longer impaired, and is not disabled. The medical model dismisses Madonna's perspectives as impaired awareness resulting from her severe brain injury. But for the social model, which claims to respect people's self-definitions, people like Madonna challenge what we understand by the concepts of disability and impairment.

Madonna not only refuses to identify as disabled or impaired, she also refuses to have any contact with the disability service system, because she thinks it would mean giving up her independence. When I asked her if she had ever had disability support services in her life, she replied:

> I don't. Never heard of it. And I wouldn't. If I was able to get it I suppose you'd have to pay for it anyway. Even if they offered it, I wouldn't accept it anyway because what they do and what you do is two different things.
>
> *What do you mean?*
>
> Well what they want you to do and what you want to do is two different things. See you might want to go, you might want to go walking, go for walks. Like I go for walks every morning. I will go around the blocks and go down to the ferry and back. And sometimes I go around the blocks and go out that way.
>
> *It's a fair walk to the ferry . . .*
>
> So I do that. They mightn't like you doing that so you've got to go back into their habits.
>
> *Yeah, so you don't want to give up your independence?*
>
> No, no.

Madonna said to me that she does not tell people that she has had a brain injury at all. Sometimes, depending on the context, she tells them that she had a "headknock." I asked her why she wouldn't call it a brain injury:

> I had a headknock, but I wouldn't say (to other people) that I sustained a head injury. I think they might think I was different. They'd, quote, "freak" I reckon . . . But, if you didn't tell them you had a head injury and you got emotionally upset, start yelling and throwing tantrums, I suppose they'd realise that there was something drastically wrong or you'd react in a different way.

As these comments illustrate, Madonna has struggled to come to terms with the fact that other people have told her that she has had a brain injury. But in many respects, she is not alone. Many people with a brain injury experience significant problems with awareness. A period of profound confusion is also common. It should be expected, then, that this injury would result in difficulties with the process of identifying disability or impairment.

Like Madonna, Larry has also used the strategy of minimization and concealment in order to hide the nature of his impairment:

> With the paralysis, it took me, it was noticeable to everyone but over the years, over the coming years—oh how do you say this—I found ways to cover it up so it wouldn't be so noticeable.
>
> *Like what?*

> Well if I couldn't do something I wouldn't attempt to do it. If I tried to lift something, I'd try and put most of the weight on my right arm. Which I found later on was the wrong thing to do because I strained my right side so many times. I ended up in hospital on many occasions because of it, because I strained so badly.

Cliff also uses a strategy of concealment. He wears a hat whenever he is in public, to hide the scars on his head from the operation on his brain. He calls the area a "nasty big scar" and is incredibly self-conscious about it. Interestingly, he more often than not identifies as someone who has been sexually abused rather than someone who is disabled. He feels that the sexual abuse he experienced as a child led to a number of risky activities, such as drug-taking, which then induced his stroke. Cliff told me that he sometimes sees disability as an effect of another identity: being someone who has experienced profound sexual abuse. He does identify as someone who is impaired and disabled, sometimes, but these are fluid identities. He prefers to call himself a "survivor" than a disabled person. He is not only active in the brain injury survivors group, but also in a group of adult survivors of child sexual abuse.

Cliff's case is also interesting because he adopts different identities at different times. He has been repeatedly admitted to psychiatric institutions and therefore sometimes defines himself as someone with mental health issues. Sometimes he says that he becomes "paranoid," and this is his label for mental illness. But his connection to the mental health survivors/users movement is tenuous. He has ambivalent feelings about identifying as someone with mental health issues. He also feels that the mental health system and mental health user groups do not acknowledge the unique features of his mental illness which are associated with his history of brain injury. Also, he does not want to identify with this group when he is "well"—only in times of acute distress does he acknowledge this identity. He does fear involuntary committal, and is conscious of the stigma attached to mental health, and this seems to be one of the reasons he avoids all contact with the mental health system whenever possible.

Unlike Cliff, who states that he was always aware that he had a brain injury, Kirsten did not know what had happened to her. She experienced a significant period of confusion after her traumatic brain injury and she could not understand that she had a brain injury. Later, when she remained confused, she could not understand why she was readmitted to a locked ward at the hospital. Her case is interesting because it clearly shows that at the time, she neither identified as impaired nor disabled. She did not see any similarities between herself and the other people in the ward, who she called “spastics” (sic). I asked her about her experiences in hospital and she replied:

> Okay, well, the actual hospital part after I came out of the coma, I have no idea! I can’t remember that at all. And what happened from then, after—I’m not sure what date—I got out of hospital and went back to my parents’ home. Now that was when I started realising now something’s not right. I don’t think I live here. Then one particular morning I was in the shower, I got out of the shower, I got dressed, and looked in the mirror. I thought something looks weird. My hair looks weird. So I go down to the dining room and I said Mum what happened to my hair? And she didn’t sort of didn’t say much, she just looked at me. And then I looked out to Mum’s front verandahs and I said, ‘Mum where’s your car?’ That’s when she said you crashed it. And I sort of laughed and I said, ‘You’re jokin’!’ I said, ‘Is it getting fixed?’ She said ‘No, it’s written off.’ ‘Oh! Was I in hospital?’ And she told me and I said, ‘Oh weird!’ And that was it. Then the next day my parents got a call from the PA explaining that I’d have to go back up to the Brain Injury Rehab. So my parents took me up there and I had no idea. I thought I’m not staying here! Evidently my parents didn’t like it either, the actual place. They thought this is really not nice. And my parents asked one of the doctors can they take me home and bring me up everyday and the doctor said no, got to stay here. So very reluctantly I stayed there. I was not the nicest person in the Rehab and a lot of people would be able to tell you that. And I was there for a couple of months I think. No, did not like that at all! Didn’t like the atmosphere, the people. Now when I say the people I mean, I could walk, I could talk, I could eat by myself, I could shower. So all of these people to me were spastics. That’s how I looked at them, not realising that we have the same injury but obviously affected in different ways. So no I didn’t like it at all. Didn’t make any friends because I didn’t want any of them. The Rehab people, the OTs and such, they could tell you themselves, it was not very good. And I made sure I told them. And everyday my parents would come up I would have a bag with some clothes and I would run straight to the door. Because they ended up locking the doors because I tried to escape quite a few times. And my parents, you know, it did break my heart with me just standing there wondering why aren’t they taking me too.
>
> *It must have broken your heart too.*
>
> It did! I was confused, I thought why? What am I doing here? Youse can take me. You know, you’re my Mum and Dad, you can take me. I don’t like it here! And oh they, as people would know, everyday you get asked so many questions.
>
> *Yes, that’s right, that’s right. So you get asked all these questions about things like . . .*
>
> Your name, yes. Who’s the prime minister? Blah, blah. Now obviously

> for quite a while, me being a smart arse would just answer like a smart arse, not knowing that if you do get these questions right for so many days in a row they think about letting you out. So then when I found that out, quick smart I turned around and then I answered the questions correctly, very nice . . .

Kirsten now manages her impairment identity by minimizing other people's knowledge about her accident. She says that when she goes for job interviews, she tells the interviewer that she lost a pet in the accident and would prefer not to talk about it:

> Because I'm not going to lie. All I'm really going to say is listen, can we not talk about it, I lost a pet in that accident. Now in one way that's not really a lie because my pet was my brain—that's gone.

Kirstyn has a different position in public to what she has in private. In public, she often defines herself as neither impaired nor disabled. However, when she is with the people she calls "brainys," she identifies as both disabled and impaired. This is again interesting because it demonstrates the fluid and malleable nature of identity.

This brief discussion of the identities adopted by the participants in this study reflects the fact that people with brain injuries are a diverse group. Some spend a great deal of time and energy integrating this experience into a new identity, others try to forget about it completely, some consider it marginal to their identities, others structure their lives and interests around it. The queer theorist Eve Sedgwick (1990:36) once wrote that "There can't be an a priori decision about how far it will make sense to conceptualize lesbian and gay male identities together. Or separately." Perhaps this discussion leads to a similar conclusion for disability studies—that the connections between disability and impairment identities are complex and nuanced and need deserve careful scrutiny.

DEALING WITH EMBODIMENT

Brain injury is not just a cognitive experience, it is an embodied one. The brain is intimately connected to human corporeality. For survivors, the importance of embodiment is twofold: first, it is associated with a sense of becoming a different person in the same body as before; and second, embodiment is central to the experience of coma and near-death experiences. The brain injuries we have sustained have caused significant changes in every one of us. Every member of the group acknowledges that we have experienced major physical, cognitive and emotional changes. These changes are so significant that many of us feel that we have become completely new people. The discourses in which we have been framed have also been changed—in the past members of the group have been recognized as competent adults but now their competence is continually challenged on the basis that they have been identified as having brain injuries.

Rick has dealt with the changes in his embodiment by redefining himself. He calls himself "The Recycled Man." The full effect of his brain injury was emphasized to him continually during his six months as an inpatient, and also during his lengthy rehabilitation. Visits to the Brain Injury Day Centre further reinforced his sense of difference and changed embodiment. Neuropsychologists have worked with him extensively and have continually emphasized to him that he needs to have a positive attitude. The effect of these power dynamics can be seen in the following comments:

> I feel as though I have gone down a big dark tunnel to near death itself and come back out to tell everyone what it has been like . . . I am very thankful for this accident as I am now the Recycled Man. I have a chance to start life all over again where most of us only have one life, I feel as though I have had two lives in a visible sense.

Like Rick, Cliff had a long period of hospitalization, followed by many visits to the Day Centre at the hospital. He was operated on for a ruptured aneurism and subsequently had radiation treatment and extensive sessions with neurologists, neuropsychologists and psychiatrists. One result of his brain injury was serious paranoia and he sometimes became violent and aggressive. Neuropsychologists worked with him to control his emotions but they had also made him more acutely aware of his embodied changes like memory problems and emotional instability. He has been involuntarily admitted to a psychiatric institution on numerous occasions. Cliff's experience shows that people with a brain injury not only have a radical shift in the experience of their bodies but also in the ways in which these bodies are interpreted socially. On one occasion he spoke to me about these treatments and he became very agitated and upset. First he began crying about the way other people have responded to the scars on his head. He felt that once he had been labeled brain injured, everyone's perception of him had changed. Also he felt that once people saw the scars on his head they made assumptions about his cognitive abilities. Seeing his distress, I drove him to the offices of a neuropsychologist who had previously provided counseling for him.

We spoke again at a later date. He was in better spirits on this occasion. At the time he maintained he had changed fundamentally as a result of his brain injury:

> In a lot of respects I have become a new person. Yeah. Definitely. Some really good new traits and some not so good ones. I have less tolerance to stress, my memory is definitely worse, my emotions fluctuate. The more I have found out about society's view of disabled people, the more anxiety it causes me. But I am slowly putting that behind me . . . I appreciate so many more things than I ever did in my life, like my music, the trees, birds, the environment. I've got a new found self-confidence when it comes to interacting with people. But that fluctuates. My self-esteem does depend on other people's view of me, at times.

In my own case, I too had numerous hospitalizations and evaluations from neurologists, neuropsychologists, neurosurgeons, and allied health professionals such as social workers and physiotherapists. One neurosurgeon said to me:

> Get it into your head you're brain damaged. You'll never be the same again. You can't recover from brain damage.

Not only was I facing embodied changes in terms of walking and talking, thinking and acting, but I also was being resocialized into the role of someone with a brain injury. Around this time I read the book *The Making of Blind Men* by Robert Scott (1969). Scott argued that the "blindness system" socializes people with vision impairments to display certain attitudinal and behavioral patterns. I felt that the medical gaze was similarly encouraging me and the other survivors I knew to identify ourselves in certain ways and to behave accordingly.

This socialization process was an essential element of my personal response to my embodied changes. Accordingly, I found it difficult at first to adapt to a whole new way of thinking and behaving. The stress of continually seeing doctors took a significant toll on me. My "recovery diary," which records a lot of the lessons I learned on my journey back from brain injury, is a useful reminder of how I was feeling a few years ago:

> There is a deep well of sadness inside my heart which overwhelms me with feelings of hopelessness and defeat. I cannot picture anything ever changing for the better. Whether I want to live is something I think about as a day by day proposition. Often, I wish I were dead. I feel like so much of "me" has been killed in the accident, I am not "me" anymore.

Although I have confronted such depression and now have a generally optimistic outlook on life, I still struggle, thirteen years on. In the long-term, I have found the confusion and disorientation from my own head injury the most difficult to manage. I have struggled with language, and sometimes it has been too difficult for me to speak. I cannot form the words that I have wanted to say in my brain, let alone in my mouth. Sometimes, I try to organize my thoughts but irrelevant material comes to mind—like numbers. For instance, on one occasion I wanted to call out "please help me," but all that came to mind was "two to the power of six," and I couldn't even say that. I was left silent, unable to communicate. I couldn't remember how to make my brain tell my mouth to say words. So I lay in silence for about five hours. Another time, I wanted to say that my head wasn't working properly, but all I could think of was the word "chocolate." And another time, I thought my dog Wally was my Mum. Like someone with dementia, I have been lost in the tea room at work, and wandered around aimlessly until I rediscovered a familiar face or place. These sorts of embodied experiences, which are experienced both at the cognitive and physical level, have been very emotionally trying.

Reg has had a similar change of self. His whole perception of life changed because his memory and life skills were suddenly gone:

> One day I was a human being, and I've got twenty years of experience in everything I've ever learnt from the age of birth . . . The next day I woke up after the head injury, I didn't remember any of that . . . It's like a computer, it's the hardware that's been totally wiped out, there's nothing on it anymore. You're a twenty-one year old, you've got the mentality or the life experience of a one-year-old. All these things are different. Took me two years to just come to terms with where I was and what I was.

Reg's embodied changes resulted in profound confusion. He received his first brain injury as the result of being assaulted and hit on the back of the head. His second injury was also the result of an assault—he was violently pushed off a third floor balcony and received a fractured skull. When the police were called on the second occasion, Reg was under the influence of drugs and alcohol. He was not considered a credible witness and charges were never laid against anyone. Reg's experiences are an important reminder that power dynamics are often at play in causing brain injuries as well as in responding to them.

Kirsten agrees that you become a different person after a brain injury, but is tired of thinking about the person she used to be:

> I'm sick of looking back at what I used to do. Now I know really what should happen is I should have a funeral for myself because that's not

> me anymore, it's not me . . . I'm not used of it. I don't like it. I reckon I'm a dumb me. Dumb! I don't like . . .
>
> *You don't come across as dumb.*
>
> No, well when I say that, like, I do compare. Every now and again something will come up and I'll think, oh, that's not me, I don't do that.

Kirsten struggles with her embodied changes and her dream is to return to her previous cognitive and physical state:

> Simply because getting back to the old how I've been my whole life. I am pig-headed and I don't want to give up. I won't. I won't give up. I will keep trying because I have got all the qualities there for a job, as simple as that. And, well, I can't see nothing wrong with me. Now maybe there is and I will be glad to listen to that if there is something wrong. Fair enough, but I can't see it. I cannot see myself being unemployable.

The struggle over Kirsten's embodiment is one which she conducts in both the public and the private realm: in her self-perception, in relationships, and in her struggle to achieve employment in the labor force.

J also acknowledges the significant changes in himself:

> I am now limited to what I should be able to do because of the brain injury, and it doesn't move as well. It's not as coordinated, not as quick. And well because of all those things, I may not look like many other people. I don't have to ask, I know that many people already have the answer in their head but they can't just get it out or do it as fast as the average Joe Blow. So mostly I'm confined within those limits.

But J does not believe that the organic damage to his brain is the only reason he has struggled so much after his injury. He is quite certain that the lack of understanding about head injury in the community has made his struggles much harder. He says that people often confuse brain injury with intellectual impairment, and also assume that a person with a brain injury is deaf:

> People think you're a bit deaf, and they talk a bit louder, and they talk a bit slower so you can understand what they are saying. It gets very—what's that word—monotonous. After a few times, after you stop laughing about the way they do that to you, you get pretty agro at it because I'm no different. I mean not really. I am what I was before my

> accident. I still have my brain. It may move in a different way because I mean I'm within a broken shell and my brain moves a little bit slower. But I mean it annoys me how people automatically—what's the word—have assumptions about how you are, what you should feel, what you shouldn't feel. I mean they can all [blows a raspberry] themselves because I need to try to reinvent myself and get a better quality life.

J stresses that a head injury means that a person has to start again:

> You have to reinvent yourself, and you have to work out where you were, what you're doing, what goals you want to achieve for yourself because no one else is going to help you. I mean they'll help you to a certain standard and that's all you're entitled to.

J's comments reflect his struggle to assert his continuing human rights in the face of power regimes which regarded someone with a head injury as a lesser being. People with severe brain injuries are often represented as not quite alive, but not quite dead either. This has real implications for people's lives because they are not supplied with support and opportunities to grow. Embodied cognitive changes are not only assumed to be permanent, they are also assumed to reduce the humanity of the individual. In the words of one critic, Winslade (1998: 121), "While this may be life, it is not human life."

Embodiment is also an important theme associated with the experience of coma and near-death experiences. Of course, not all comas involve near-death experiences and not all near-death experiences involve comas. However, Rick's experience of coma is illustrative of the embodied nature of the experience. When he was injured, Rick's wife was told that he would be a "vegetable" for the rest of his life. At the time, he could not walk, talk or eat food. Yet the sense of embodiment remained with him; he felt aware of his environment in the hospital but was unable to communicate this. He could hear doctors and nurses discussing his case around him, but he was unable to respond. Likewise, he was aware of visitors. But he could not move or speak, so he had no way of letting them know. He distinctly remembers one of his experiences from the time when he was in a coma:

> One day two of my friends came to see me with their little baby. Even though I was in a coma, I heard them talking and the father put the baby in my arms and I felt it lying there.

Rick's wife read to him while he was in a coma, and when he emerged from the coma, he picked up the book and began reading at the exact page where she had been reading to him. Even when he was in his least responsive state and could not communicate with the world in any meaningful way, Rick still retained an embodied sense of self and some awareness of the environment around him.

Rick's embodied changes led to significant confusion:

> Oh it was pretty weird. Because I was very disorientated. I was having very vivid dreams. I didn't know which was reality. To me, when visitors came, the dream would be over like the visitor, overladen dream. So I imagined I was dreaming bits of that were the same thing even though it wasn't. Vivid dreams. In one of the dreams I dreamed that the whole hospital was on-board a ship on a freshwater lake in Tasmania, probably because in '75 I'd been to Tasmania for my honeymoon. Somehow my mind was really mixed up. Also I dreamt that Robert in the bed opposite me in critical care, in M7. I was in M7 in PA Hospital by this time, out of intensive care. I dreamed that Robert—he was dressed in green hospital pyjamas—he was a green tree frog, and he'd come up. We had shrubs. Harriet and I lived on a big log platform in the rainforest. Because Harriet brought in a big rainforest picture . . . I dreamed that Robert lived down in the creek, and come up and lived on the platform with us. And we'd guided him to his parents in Ipswich—don't ask me how I knew that! Where his parents lived, then he got beaten up by a gang of cane-toads, and that was how he'd come to be in hospital. So somehow my memory, everything got very confused . . . Also some friends of mine came in, and we were outside in a wheelchair talking about gardens at home, because I used to be a landscape designer, and my friend, Russell, he had big practical hands. I was saying to him, 'Russell, can I check your hand? I'm in a big dream I can't come out of it.' He would take my hand and I would suddenly come out of the dream.

Embodiment is also an important theme in the narratives of those group members who had near-death experiences. Reg said to me:

> Yeah, I had near-death. Yeah I did die but I was brought back to life . . . one minute I was lying down screaming in agony, the next minute I'm engulfed by the light, the lights just encouraged me to want to surrender my life. I don't know whether I'm lying down or standing up. It's all white. It's beautiful, really feels great. I walked around in little circles trying to get away from where I was. That only lasted a few minutes before I was brought back to life.

Reg talked about an embodied transition from intense pain to a sense of peace and painlessness. He was engulfed by a sense of light which was very peaceful. Traditionally such tales of near death experiences are looked on with considerable skepticism. However, a number of people in our group report these experiences as being incredibly significant in their lives.

Madonna technically died on five occasions. She relayed her near death experience in the following manner:

> When I died a couple of times, I went up top and saw Peter, Saint Peter.
>
> *Tell me about this. You've never told me about this!*
>
> Didn't I say that? I saw him and he said to me 'It's not your time yet.' What do you mean it's not my time yet? He goes, 'No, it's not your time to come in.' I said what do you mean? He goes, 'It's not your time to come in to the pearly white gates.' Oh, okay! So, your number's not up yet. And I said, so when's it going to be up? And he goes, 'In '99. And then it's just zip! Get right down there!'

Madonna also reported a vision of the Virgin Mary:

> Mary came down and seen me when I was in M6 [the hospital ward] there. And she came down and told me, 'I want you to do this and that.' She told me to walk and I did it in front of her.

At this stage Madonna had never been able to walk since her injury. A physio came and visited her and encouraged her to do exercises which would help her walk again. Madonna could not see the point of these exercises as she felt she had already walked in her near death experience.

> Then the physio said to me, 'Okay come on Madonna, try and walk.' And I said to her, I've already done it!
>
> *But she didn't see it.*
>
> No.

I would probably be more skeptical of these near death experiences if I had not nearly died myself and experienced a quite transformative sense of light, peace and transition. Like Reg, I was transformed from one place where I was in enormous pain to another where I was surrounded by light and was completely pain free. I felt immersed in this light. I felt that I was taken to another place. I had a sense that there were beings of some sort, almost shaped like clouds. These beings spoke to me, and told me to relax because it was my time to die. I argued with them. I said, 'No, send me back down.' They said, 'Everyone is like this at first. You just need to calm down and accept it.' I told them no, there were things that only I could do so they should send me back down right away. Another celestial being came to see what the argument was about. I had a sense that this being had more influence than the other two I had spoken to. I repeated to this being that there were things that only I could do, and that I must go back down. This being seemed to look into my future and said 'Yes you must.' I had a sense I went back down a tunnel and came back to this life. For me this was a strong embodied experience. I reported this experience to my family while I was still in hospital and I did not have time to make up such a bizarre story.

People with brain injuries who report such experiences are often seen as psychotic or delusional. They may also have concurrent psychiatric symptoms which diminishes their credibility in the eyes of many people. However, I have included this data because I am trying to be respectful and faithful to what the participants in this study have reported.

COMPLICATING DISCUSSIONS OF DISABILITY AND OPPRESSION

In this section of the chapter, I intend to outline some of the different meanings of "disability" raised in this study and to highlight the differences between those who view disability as a form of oppression and those who support a minority model of identity. I also intend to deconstruct the use of term "oppression" to see whether it is sufficiently rigorous as a concept to describe the complexities of the power dynamics I am describing.

To define "disability" solely as the "social oppression" of people with impairments is to position it as a completely negative experience. But to do so is to promote one definition of disability—that preferred by advocates of the social model—over other, competing definitions. Some of the discussions undertaken by survivors in the course of this study relied on a completely different concept of disability. I am thinking in particular about a few meetings where we discussed the ideas of disability pride and disability culture. Throughout this book, it has been suggested that many social movements have engaged in flaunting in order to open a transgressive cultural space which celebrates a particular identity. The post-colonial concept of Negritude is one example of such a cultural redefinition of identity. Unfortunately, however, very few authors who use a social model approach have placed much value in the idea of re-appropriating the term disability as a term of pride. That is not to say such efforts have not been made by disability activists around the world—rather, it is to suggest that connections between this reappropriation of the term disability, and the standard definition used within the social model of disability, is tenuous.

By defining disability solely as a form of "oppression," the social model makes the terms "disability pride" and "disability culture" nonsensical. One participant in this study reflected on the negativity of the social model towards disability by commenting that the social model saw disability "as a glass half empty," but he wanted to see it "as a glass half full." He found a space to do this in a redefinition of disability, in a way that was more akin to some of the American minority model approaches. In this context, "disability pride" does not mean being proud to have a particular impairment. Nor does it refer to pride in being oppressed on the basis of impairment. And it does not refer to pride in the successes which disabled people have achieved in spite of disabling barriers. It is, instead, about celebrating a shared identity. The term "disability," in such discourses, refers to membership of a minority group rather than the experience of oppression *per se*. The comments of this participant reminded me that there needs to be a space in the social model to broaden our discussions so that such alternative and expanded definitions of disability can be acknowledged and discussed. Within such discussions, of course, there needs to be thorough critique of the essentializing and exclusionary tendencies of such a discourse.

Nevertheless, the development of cultural spaces where disabled people redefine their identities is an important mechanism through which they can understand, resist, struggle and grapple with their experiences (Munford and Sullivan, 1997). For some, the celebration of "disability culture" is a revolutionary act, based on identifying with other disabled people, recognizing shared experiences and valuing disabled ways of life (Brisenden, 1990; Peters, 2000; Vasey, 1989; Wade, 1994). Disabled people engaging in identity politics where we take pride in ourselves and our bodies, believe in and support one another, is therefore a major theme of the disability rights movement internationally (Charlton, 1998: 22). A key element of this struggle is the assertion of an alternative set of values which challenge dominant ideas about beauty, normality and difference and which rethink the meaning and value of disability (for instance, Hahn, 1988; Schenkel, 2000).

Not only did some of the data in this study challenge the social model's definition of disability, it also led me to critically interrogate the assumptions about power which underpin a great deal of the literature on disability as a form of "oppression." Michel Foucault's writings on power have particularly influenced my thoughts on this issue. Foucault discussed power in many of his books, including *Discipline and Punish: The Birth of The Prison* (1994) and *The History of Sexuality, Vol.1* (1990), as well as other lectures and essays. Foucault did not develop an entire theory of power, but did provide an "analytics" of power which strongly challenged traditional top-down notions of oppression and liberation (1990:82). In *The History of Sexuality: Volume One* Foucault (1990: 83–84) outlined some of his problems with the traditional notions of repression and oppression. He argues that a "juridico-discursive model" underpins many conceptions of power. This model assumes that power comes from above and it positions power as a negative force, relying on rules, prohibition and forms of censorship which operate in a uniform and comprehensive way.

The social model is a liberationist tool. However, Foucault's arguments have been very influential in challenging the discourse of "liberation." Foucault believed that power does not operate this way: power is not simply negative and doesn't just take the form of prohibition and punishment. Foucault argued that power comes from everywhere; it is not a thing, an institution, and aptitude or an object. Power is a complex strategical situation which is mobile, relational, shifting and unstable. Wherever there is power, there is resistance. We will never be "free" or "liberated" from power—it is invested in us, and helps us understand who we are. Foucault stressed that knowledge and power are intimately and productively related, but not the same. In *Discipline and Punish,* Foucault (1995:194) adds:

> 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 belong to this production.

In this paragraph, Foucault was criticizing a particular approach to power which assumes that it is only negative, and comes from the top-down. Unfortunately, however, these are precisely the sorts of assumptions that often underpin the social model of disability.

Richard Abberley (1997) is one of the social model authors who is clearly attached to the sort of "juridico-discursive" model of power that Foucault was challenging. In an oft-cited essay, Abberley (1997: 162–163) argues that to position disability as a form of oppression is to make the following claims:

> At an empirical level, it is to argue that on significant dimensions disabled people can be regarded as a group whose members are in an inferior position to other members of society because they are disabled people. It is also to argue that these disadvantages are dialectically

> related to an ideology or group of ideologies which justify and perpetuate this situation. Beyond this it is to make the claim that such disadvantages and their supporting ideologies are neither natural nor inevitable. Finally it involves the identification of some beneficiary of this state of affairs.

It should be evident from this quotation that Abberley implicitly assumes that power is a negative thing, something which people or an institution possess, and which is used by the powerful to constrain the powerless. Foucault (quoted in Mills, 2003: 36) challenged such an approach to power by asking "If power was never anything but repressive, if it never did anything but say no, do you really believe that we should manage to obey it?"

Interestingly, Foucault's criticisms of a structural approach to oppression actually parallel in some ways the criticisms that E.P. Thompson (1979) made of the orthodox Marxism's structural approach to class. Thompson rejected the argument that classes could be defined simply by relationship to the mode of production and instead sought to identify the complex and contradictory processes which led to the development and maintenance of class dispositions. In this regard, he focused on the patterns which emerged over time in social relations, values and institutions (Meiksins Wood, 1982). Thompson's absolute rejection of economism and mechanical determinisms and his emphasis on the cultural, experiential and ideological elements of class resulted in increased emphasis being placed on working class cultural and political activities and more attention being paid to human agency and resistance.

Likewise, rather than highlighting repression, Foucault focused on an alternative social dynamic. He drew attention to the fact that wherever there is power, there is resistance. It was suggested in Chapter Three that one of the problems with the social model is that its structural focus may lead to a sense of disabled people as trapped and rendered helpless by disabling barriers. Foucault's arguments suggest that this flaw may be linked to a wider problem in the treatment of power. In order to avoid such a disempowered image of disabled people, it was suggested that disability studies could examine the ways in which disabled people exert agency at the local level. Foucault's approach to power, which foregrounds resistance, is one way to identify such social dynamics (Mills, 2003). Such resistance can occur in many ways, including poetry and disability arts, personal and collective campaigns which challenge disablism, transgressive acts and flaunting, and a range of other social practices. In order to promote a more balanced appreciation of the efforts of the participants to resist disablism, I will now identify the actions which participants, individually and collectively, have undertaken. I will offer an alternative image of brain injury survivors, neither the tragic victims of their impairment, or the victims of disabling barriers. Instead, I offer a picture of brain injury survivors in struggle.

Foucault's "productive" notion of power could be linked to broader discussions about the ways in which identities such as disability can be simultaneously empowering and disempowering. The work of queer theorist Judith Butler (1997:29) around "subjection" is also helpful in this discussion. Butler, following Foucault, defines "subjection" as both subjecting someone to a form of power and also making them a subject. "Subjection" is different to oppression in many respects, but principally because it has both a negative and a positive dimension. That is, our identities are not only simply negative reflections of power imposed on us, but simultaneously allow us to speak from a certain position of power. The idea that having a disabled identity can be both empowering and disempowering may explain some people's ambivalence around it—but it also challenges us to critically interrogate some of the traditional assumptions about power which underpin the social model of disability.

In this context, it may be useful to discuss the term "survivor" and identify some of the reasons for its popularity among many members of the brain injury community. It is important to recognize that people who advocate the use of this term are engaging in what the postcolonial critic Gayatri Spivak (1990:15) calls "strategic choices of essentialism." The rationale for such essentialism is not to deny differences within the group, but to mobilize around the identity for subversive purposes. The term "survivor" is not unique to people who have experienced a brain injury—far from it, in fact. Many battered women chose to describe themselves as survivors of domestic violence (Gondolf and Fisher, 1988; Walker, 1994), as do some people who have experienced rape, sexual abuse and incest (Hall and Lloyd, 1989; Sydney Rape Crisis Centre, 1984). Some of those who have experienced potentially-fatal diseases such as cancer or leukemia have also chosen to call themselves survivors (for instance, Fromer, 1995; Patenaude, 1999). The term "survivor" has also been adopted by many users of the mental health system, to emphasize the fact that they have survived in spite of a mental health system which is highly oppressive (Beresford and Wallcraft, 1997; Wilson and Beresford, 2002).[1] In some ways, the "survivor" discourse appeals to many groups because of its links to hegemonic discourses around power and agency. The term "survivor" is one which empowers. It is full of agency. It is the opposite, in many ways, to the traditional oppressive images which have been attributed to women, disabled people and children—images of helplessness and dependency. Also, survivors are not tragic figures—they are remarkable and resilient, rather than weak and vulnerable. "Survivors" may have experienced terrible things, but they are not defeated by them. They are not "victims."

Far from being passive and dependent victims of brain injury who need sympathy and charity, we have been remarkably active in trying to create better lives for ourselves and for people with a brain injury more generally. We have exerted our agency in many different arenas, including in our personal relationships, our relationships with other survivors and their families, in our dealings with Government representatives, disability advocacy groups, service providers and the media. Our public speaking at Conferences and our use of certain legal strategies have been other ways in which we have tried to influence the outcome of events. To paraphrase Butler's work on subjectification, we have been simultaneously disempowered by being positioned as people with a brain injury, but we have also used this identity as a source of strength as well.

One of the main things that people in our group have done has been to challenge stereotypes about what it means to be brain injured. For instance, as part of reclaiming the right to define our own experiences, group members participated in a "Survivor Day" tree-planting ceremony aimed at celebrating the lives of people with a brain injury and remembering those who had not survived. The following messages indicate the level of support which survivors gave to this event:

> You have my complete support as I am a survivor from a TBI and had to fight really hard to avoid being sent to a home to vegetate. Such a waste as I am now, 6 years later, a very much more aware and healed person. Peter Buckingham
>
> I don't have any words of wisdom, except to say that while I do have many debilitating consequences from my TBI, I nevertheless have developed a BETTER QUALITY of life than I had pre-TBI. I am spending much more time now helping others and I am more focused on making better use of those assets that remain. GOOD LUCK ON YOUR VERY SPECIAL DAY!!! LOVE, KAREN
>
> Hi Living with the so called hidden disability is very hard at times, but I say that I have a impairment, it's you society that has a disability in understanding. I live with my impairment, you stop me trying to get along with my life. Jim Mc Nabb
>
> I hope that you can help educate others that people with TBI's can be someone in their family or even themselves. We need to have support

> and understanding from others to be able to survive. Good luck with your doings. Janet
>
> Survivors: Although we all may be worlds apart and different in many ways, we share a common thread inside that helps us help ourselves. We know each other's secrets but we don't even know each other's names. We are trying to survive in a society that doesn't understand us and sometimes I wonder if they try. So those of you who can, stand up and speak the truth. Make other people hear you instead of just trying to make them listen. Survivors this is our day to celebrate our successes however small they may be. Never doubt your worth or your excellence in this struggle for a better more understanding world in which we all find ourselves. And please reach out to other survivors who may not be strong enough yet to accept who they are or be able to understand who they have become. Sometimes our courage can be found in our disability. You never know, courage can come from the most unlikely places. Be strong, be caring, be brave and don't be afraid to seek help from those who have been where you've been. And above all else be true to yourself. You are a survivor and you are extraordinary. Reggie
>
> What a wonderful idea, my best wishes to you and the group. Marie

Part of this strategy involved flaunting: deliberately transgressing social conventions in the process of challenging traditional notions of what it means to be "brain injured." In this regard, the group developed an alternative set of values which appreciated, rather than devalued, behavior which has traditionally been associated with brain injury. Disinhibition, for instance, was generally encouraged rather than frowned upon. Identifying as "brain injured" was said to make you "one of the cool kids." And despite this air of light-heartedness, the group was still committed to the very serious message that people with a brain injury deserve exactly the same rights and choices as every other member of the community. One of the local television stations came and filmed this event, though it did not make it to the news as a major sporting event happened on the same day. Some of the members of the group commented that their lives seemed not to matter to the media when a more "newsworthy" story was available about sport. More generally I saw it as a reflection on the structural powerlessness of a group of disabled people to influence the mass media.

Our agency is constrained to the extent that the power to label someone as brain injured still resides with doctors and the service system. However, members of our group have tried to assert our own values and define our own experiences in non-traditional ways. We have asserted our right to speak on the issue of brain injury on the basis of our experiences. These experiences are our expertise. For instance, Rick has published his own book about life after a brain injury and the problems of falling through the gaps in the service system. He also gave a series of seven talks to medical students at the Royal Brisbane and the Princess Alexandra Hospitals. "J" attended a meeting with a federal politician in order to lobby for a better deal for people with a disability. He challenged this politician about services and when the politician replied that things were going to get better, "J" simply said, "That'll be the day!" Such a blunt assertion of rights and pessimism about the future is quite characteristic of many people with brain injuries but non-disabled people will often find this behavior very challenging.

In asserting our agency, we have sought to influence the social and physical environment in which responses to brain injury occur. For instance, in order to improve the rehabilitation practices at the hospital Rick wrote letters to the staff at the ward in which he was a long-term patient. Other members of the group visited the hospital in order to encourage new survivors to see that you can have a rich and full life after brain injury. Some members refused to visit the hospital, on the basis that they saw the place as "a hell hole." Four members of the group also visited brain injury survivors in nursing homes, offering them emotional support. One of the members of the group was previously a long-term resident of a nursing home and is acutely aware of the injustice associated with placing young disabled people in aged care facilities.

In terms of organizational strategies, we have set up email links, a newsletter, and a regular meeting time for survivors to meet and support each other. At these meetings people talk about what is going on in their lives and what issues are important to them. Three of the members of our group have become active on "tbichat," an Internet chat line for survivors of a brain injury and their families. The people who we have met online have sometimes emailed our group letters of support. For instance, eight people from "tbichat" sent messages of support to our group for the survivors' tree-planting day. The Internet connections which we have made also led to the establishment of an informal alliance between our group and Bear In Mind, a Melbourne-based survivors' group. We have shared information about our campaigns and about our personal struggles with Bear In Mind members.

Perhaps the single most important contribution of our group has been individual visits to people's homes, to hospitals and to nursing homes. This individual commitment has been the primary strength of our group, as it has forged genuine social networks around very vulnerable individuals.

Sometimes people have commented that this support has kept them alive. Such comments have reminded me never to underestimate the radical power of friendship. Family members have also commented on the importance of this support to them. One member has regularly been admitted to a psychiatric hospital and his mother told me that our group's support has been instrumental in keeping him out of that institution on many occasions when he would otherwise have "lost it." Listening to people's stories and validating their experiences has led to the development of personal connections which are strong and enduring. Some of these connections have lasted more than four years.

People's ability to influence economic, social and political agendas is greatly influenced by their socio-economic position. In this regard, the social exclusion experienced by members of the group (who are typically unemployed, poor, and extremely socially isolated) is a significant constraint on our agency. It means that we have few natural allies; our functions tend to be low-key, low-budget affairs. We have no access to funds which might help market the group, and no socially influential or economically powerful members. The fact that we depend on our own freely-donated time to promote change is both a strength and a weakness: it is a strength in the sense that the members are active, passionate and committed, but it is also a weakness in terms of being unable to influence wider political developments.

Our lobbying activities have nevertheless had some impact. For instance, members of our group were responsible for nationwide protests around the *Discussion Paper on the Needs of People with Acquired Brain Injury* published by Disability Services Queensland in conjunction with the Brain Injury Association and the Acquired Brain Injury Outreach Service (2000). The original draft of this plan contained no definition of brain injury, no reference to the needs of women who receive their head injuries through domestic violence, no reference to the need for services in rural areas, no references to the need for culturally appropriate services for people from diverse ethnic backgrounds, and no references to the needs of children with a brain injury. By using the Internet we were able to publicize these limitations through various discussion lists, including OZADVOCACY, the Physical Disability Council of Australia, and the Women With Disabilities Australia lists. Letters of support for our campaign were received from sixty-eight women who had received head injuries through domestic violence, and also from disability organizations including the National Ethnic Disability Alliance and Women With Disabilities Australia. Our group's networking and lobbying of other disability organizations led to the establishment of a wider consultative process. However, our group still has not been funded to conduct wider consultations with the survivor network, and without these consultations we will regard any policy outcomes as flawed.

Individuals in our group have used a range of lobbying techniques including: petitions to Parliament, meetings with individual Members of Parliament, letters to the Minister, media strategies (including both television and newspaper campaigns) and group meetings with relevant public servants. Legal strategies, including a complaint under the Disability Discrimination Act, have also been adopted when documents have not been provided in an accessible format, such as Plain English. We have also held individual meetings with a range of disability advocacy groups in Queensland including Queensland Advocacy Incorporated, Queensland Parents of People with a Disability, and Speaking Up For You. We have joined with these organizations in an alliance over the issues of younger people in nursing homes. This alliance has contained some tensions as we have been the only non-funded organization participating. Members of our group have not been consulted about many major decisions which have affected their lives. Indeed, despite our best efforts, we are frequently ignored by Commonwealth and State Departments, and by other disability organizations, and we are essentially excluded from discussions about matters of policy and program development. Despite many meetings with other organizations and bureaucrats, becoming one of the "recognized players" within disability circles has been very hard for our unfunded, marginalized and excluded group.

Our activities have been entirely funded out of our own pockets. When one considers that nearly every member of the group is unemployed, and that the cost of life with a disability is very expensive, and that nearly everyone is living in poverty, our achievements have actually been quite remarkable. Our influence, however, could have been far greater if we had funding. Our group members believe that recognition and a higher profile would come with funding. Even though we have not been able to achieve as much as we would have liked, and brain injury survivors are still very marginalized and socially excluded, members of our group feel that the process has been empowering. We have voiced our concerns, raised the profile of brain injury, made submissions and have tried to make a difference.

Research projects like this one often cannot solve all the problems which a marginalized group like brain injury survivors experience. But the involvement of group members as full collaborators has been a learning experience for everyone. It has also meant that people who have been ignored for a very long time have finally been able to voice their concerns and raise issues which are important to them. In our struggle for social change, we have also created a respectful, friendly environment where everyone's dignity has been respected and everyone is valued for the contributions they have made. Members of the group feel that what we have done has been personally rewarding. Our public actions have been complemented by many private ones. In our personal lives, each one of us has informed our friends about the lifelong effects of a brain injury or has tried to make friends with other brain injury survivors. Each member has contributed to making the group a "safe haven" where we avoid negative stereotypes about brain injury. These individual and collective efforts have taken a great deal of time and emotional energy from our group members. They reflect our passion and commitment. They also reflect our agency—our individual and collective energies directed towards the life of survivors. Although we have faced public ignorance, apathy and negative attitudes towards disability, we have created an empowering vision of real human beings who want their rights respected and who want to have a life full of options and choices. Indeed, Cliff told me that becoming involved in the group's lobbying activities made him optimistic about the future for disabled people for the first time.

CONCLUSION

This chapter has discussed a range of data which does not neatly fit into either the social or the medical models and the way they treat disability and impairment. It has labeled this data "differend perspectives" because the discursive structure of the dominant models has prevented them from being discussed. In particular, the chapter has highlighted the complexity of disability and impairment identities. Participants in this study identified themselves along a continuum of disability and impairment identities, sometimes in more than one place along this continuum. The fluid and contextual nature of disability and impairment identities became evident in this discussion. Such flexible notions of identity stood in stark contrast to the binary disabled/nondisabled divide which often underpins thinking within the social model. The chapter also considered the value of a sociological analysis of embodiment within the study of disability. Finally, the chapter drew on the work of Michel Foucault (in particular his conception of "productive power") and to a lesser extent, Judith Butler's (1997) notion of "subjection" in order to problematize the notion of oppression which underpins a great deal of disability studies literature. The next chapter will consider some of the ways in which disability studies can respond to these practical and theoretical challenges.

Chapter Eight
Conclusion

INTRODUCTION

In this book, I have attempted to move away from simplistic understandings of the experience of brain injury by recognizing the complexities of issues associated with impairment, disability, embodiment and identity. I have used an interdisciplinary approach, combining feminism, queer theory, postmodern and postcolonial literature with the traditional approaches towards disability, the medical and social models. I have consciously sought to highlight similarities as well as differences amongst participants, and have been inspired by feminist literature to focus on both the public and the private lives of brain injury survivors. I have not only examined the material elements of power, such as exploitation, marginalization and exclusion from the labor force, but also the emotional dimensions of disability, as they manifest themselves through forms of disrespect such as a lack of love, rights and solidarity. I have examined brain injury as one form of human variation which is devalued through a complex interaction of social and biological forces. I have consciously avoided simple binaries which dominate identity politics, such as the black/white or disabled/nondisabled divide. Instead, I have sought to highlight the fluid, contested and complex nature of identities. Likewise, I have engaged with feminist literature on embodiment in order to examine some of the issues which may be downplayed by a simple focus on impairment and disability.

Not only have I brought a unique theoretical approach to the study of brain injury, I have also attempted to be innovative in my methodology. I often have been positioned as an "insider," because of my role in the brain injury survivor movement, but I have consciously sought to problematize that position. I have not assumed that my own experiences were in any way representative, and have focused on the differences between myself and the other participants as well as the similarities. I have placed more importance on the methodological rigor of the study than most “insider” research. I have been inspired by some of the aims of “emancipatory” research which is gaining influence in disability studies, but I have also problematized the modernist rhetoric of “emancipation.” I have particularly questioned the dominance of the social model in some of this literature on “emancipatory” disability studies. In place of this rhetoric about “emancipation,” I have tried to focus on the ways in which this research has been non-exploitative and conducted in an atmosphere of political collaboration with participants, while at the same time allowing myself to be “somewhat independent” at the level of analysis.

A great deal of the literature on disability studies is underpinned by a problematic disabled/nondisabled divide. In Chapter Three it was suggested that various groups of impaired people, such as Deaf people, psychiatric system survivors and people with learning disabilities, may find this binary division inappropriate or ill-fitting. Furthermore, the discussion of the silencing of discussions of impairment, predominantly by male disability scholars, highlighted the fact that identity politics can be both a liberating and a disciplinary mechanism. Post-colonial literature and queer theory have highlighted similar problems with identity politics: for all their political and rhetorical value, binary identities (whether they are black/white, disabled/nondisabled, straight/homosexual) will always exclude those at the margins and therefore will always be contested concepts.

Transgressive politics, such as flaunting (inspirational mottos including “black is beautiful,” “gay is good,” and so on) have had some impact on disabled people in recent years. Identity politics have developed around a concept of disability culture, where phrases such as “crip” or “gimp” have been reclaimed. Some of the participants in this study have engaged in tentative ways with such transgressive politics, by contesting the meaning of having a “brain injury” and valuing (rather than devaluing) the common characteristics of brain injury, such as disinhibition. However, these cultural practices have occurred at the margins of community life, and may reflect a disempowered rather than empowered status in the community. People who face so many forms of disrespect (including the diminution of rights associated with disabling barriers, the highest rate of incarceration of young people in aged care nursing homes, a lack of love and friendship, or a complete denial of their humanity because of the label “vegetative state”) are hardly in a position to mount a full-scale challenge to dominant social values. Nevertheless, they are still able to exert considerable agency, and we should not underestimate their resistance.

People with a brain injury have often been positioned as incompetent and incapable of managing their own affairs. They have been seen as tragic and powerless victims. Yet the personal stories from participants in this study indicate quite clearly that even in their most vulnerable periods such as when they experienced coma or were near death, individuals struggled to exert agency. In a period of significant embodied changes and profound confusion, such agency may not have been easily understandable to the world around them. But for the individuals concerned, making a decision like the choice to continue living, or the choice to walk again, was profoundly significant. Such individual agency must not be downplayed. However, the structural focus of the social model has often meant that such agency was not given its full recognition. I hope this limitation has been overcome in this study.

Another limitation of the study is that it is based on a very small sample size. Such a small sample means that questions of generalizability need to be addressed immediately. It cannot be suggested that the stories presented in this study are in any way "typical" or "representative." In order to conduct a "representative" study, a great deal of additional resources would have been required. Nevertheless one can speculate on the generalizability of these studies by noting that many of the disabling barriers identified in this study are consistent with broader Commonwealth Government and State Government reports on brain injury—for example, *Making Rights Count: Services for People with a Disability* published by the Commonwealth Department of Health and Family Services (1996) and the *Review into Service Provision in Queensland* by Elizabeth Kendall (1991). Such reports have consistently acknowledged that brain injury survivors frequently lack basic entitlements such as appropriate accommodation, and appropriate responses to their needs.

One way to gauge the reliability and validity of a study like this is to conduct broader analyses of the conditions experienced by brain injury survivors throughout Queensland. Queensland had the highest rate of brain injury in Australia, and the failure of Disability Services Queensland to undertake such research reflects its historical neglect of brain injury. This study points to the need to do a comprehensive analysis of the situation of brain injury survivors—examining issues such as accommodation, rehabilitation, respite, community access opportunities, transport, education, employment and other barriers. In the past when surveys of service provision have been conducted in Queensland, survivors have been marginalized or have had little input. Service providers have tended to dominate policy, practice and research on brain injury in Queensland. Given the limitations of such services, and the ethical push from disability rights activists for the complete involvement of disabled people in every stage of such research, this historical neglect can no longer continue. The disability rights slogan "nothing about us without us" is apt. A comprehensive study of brain injury in Queensland needs to involve survivor organizations, and fund such organizations accordingly.

KEY THEMES

Throughout the book, a number of areas have been identified which were regarded as important theoretical issues needing to be addressed by the discipline of disability studies. These areas included recognizing the complexities of:

- Disability;
- The experience of impairment, including its social dimensions;
- Embodiment;
- Multiple and fluid identities;
- Representation;
- Individual and collective agency;
- Division, diversity and difference;
- Differences with regard to demographic variables such as gender, class, age, sexuality and geographic location; and
- The moral as well as material elements of social struggles, include love, solidarity and respect.

These issues have implications which go well beyond the study of disability—obviously, given that they involve such topics as economic inequalities and moral recognition, essentialism and identities, and transgression, assimilation and the development of counter-hegemonic strategies. This book has attempted to address these questions through a small-scale qualitative study which used an interdisciplinary approach and combined the traditional emphasis on the social and medical models of disability with insights from feminism, queer theory, postmodern and postcolonial literature. The impact of disabling barriers was discussed at length in both Chapters Three and Six. The experience of impairment was discussed at length in Chapters Two and Five. Social dimensions of brain injury, including the connections between brain injury and demographic variables such as gender, socioeconomic position and age were also discussed. The importance of embodiment was emphasized in Chapter Seven. Multiple and fluid identities were also discussed in Chapter Seven. Representation, particularly the impact of representing certain brain injury survivors as being in a "vegetative state," was also highlighted in the book. In order to move away from the structuralist overtones of the social model of disability, the importance of individual and collective agency was also emphasized, particularly in Chapter Seven. Difference, diversity and division has been a consistent theme of the study. The book has consistently sought to emphasize commonalities as well as differences. Finally, the book has sought to emphasize both the public and the private—acknowledging the importance of personal dimensions of respect and love as much as material ones such as exclusion from the labor force.

The data collected in this study suggests a need for theoretical revision of both the medical and social models of disability. Issues of rights, inclusion, respect, and diversity are often marginalized within the medical model, where the focus is on labeling the "deficits" of an impaired body. Likewise, issues of identity, embodiment and human agency are often sidelined in the social model, where the focus is on identifying disabling barriers, often from a structuralist or materialist perspective. While this book does not propose a new theory of disability and impairment itself, it nevertheless points in certain directions for future study. It is clear from the study of the medical model in Chapter Two that there are significant flaws with this paradigm. The medical model could be accused of biological determinism in the sense that it fails to consider the social context in which impaired people live. This has meant that the medical model has been silent on a range of human rights issues associated with the experience of disability. Indeed, the medical model has often been used to support the existence of segregated institutions, and Chapter Two argued that such a position was unethical. The medical model has also been criticized for its disempowering and fault-finding approach to the bodies of people with impairments. By focusing only on the perceived "limitations" of people with impairments, the medical model has contributed to a culture of enfreakment. Within this culture of enfreakment, the "abnormalities" in the bodies of people with impairments are stared at, highlighted, gazed upon, operated on, removed, and devalued through a range of cultural practices which are supported by the medical model.

In contrast to the devaluation of impairment and disability in the medical model, Chapter Three suggested that the social model has created a space where many disabled people feel confident naming their experiences as oppression and resisting those practices which rob them of their dignity. Thus the social model has made a significant contribution to the human rights of disabled people, particularly in Britain. The social model has been associated with the movement for independent living, as well as with the politicization of access issues, and the destruction of segregated institutions. These reforms have represented significant advances in human rights.

However, another major theoretical conclusion of Chapter Three was that the social model had become a disciplinary regime, which silenced people who wished to speak about impairment. For instance, many disabled feminists have spoken of their "fear" about speaking on issues associated with impairment because of the aggressive nature of responses to such discourse. They have been silenced, or at least have been made aware that their voices are being heard in a hostile climate, by certain sections of the disability movement. The social model has also neglected, or failed to incorporate, certain impairments. For instance, people with learning difficulties, Deaf people, psychiatric system survivors and people with brain injuries have been marginalized within the social model. This may mean that the explanatory power of the social model is limited in certain contexts. The theoretical challenge which this study has identified is how to create a space in which people feel safe talking about both impairment and disability, and identifying differences as well as similarities. Only in such a climate can a plurality of experiences be recognized and understood.

There are a number of theoretical challenges for disability studies posed by this book. One of those challenges is to recognize at a theoretical level the importance of embodiment for particular impairments such as brain injury. There has been, in recent years, a structured silence around the issue of embodiment, parallel to the silencing of disabled feminists around impairment. Indeed, discussions of embodiment have been dismissed as theoretically ill-informed and politically dangerous because they seem to individualize the experience of disability (Barnes, 1996; Priestley, 1999). However, silence around the issue of embodiment can no longer continue. In order to grasp the complexities of disability and impairment as a lived experience, it is necessary to grapple with difficult issues around pain, impairment and embodiment.

A second theoretical challenge for disability studies which stems from this book is the need to treat issues of identity far more seriously. There has been a tendency in the past to dichotomize identity into the categories "disabled" or "non-disabled." However, such a monolithic conception of identity stands in stark contrast to the personal narratives of the participants in this study. They have a range of impairment and disability identities and to assume commonality fails to do justice to this diversity. It is particularly interesting to note that a number of participants in this study identified as brain injury survivors but did not identify as disabled people. This position significantly challenges those writers on disability who imply that all impaired people have a common interest and common identity. The discourse associated with being a "survivor" is not unique to brain injury. It has been adopted by battered women, as well as people with an involvement in the psychiatric system. Although the social model implies that the key strategic direction for brain injury survivors should be to align themselves with other disabled people, the "survivor" discourse suggests that other coalitional strategies may be possible. There are significant links between groups which represent people with a brain injury and groups which represent battered women. Domestic violence is a major cause of brain injury among women, and there is often overlapping membership between these groups. There is clear potential for alliances between the disability and feminist movements around this issue. Whether this challenge is taken up largely depends on how successful these movements are in challenging the abuse of certain marginalized "others." Feminists need to be conscious of the rights of disabled people in the same way as the disability movement must focus on the rights of women.

Similarly, there are possibilities for alliances with ethnic groups. The lack of culturally appropriate services for disabled people from a non-English speaking background, for instance, is an issue which could be taken up by both the migrant community and the disability movement. Again there are possibilities for action by both the queer movement and the disability movement around the issue of contested sexuality. In the same way as disabled people's sexuality is often denied, gay men, lesbians, transgender people, and bisexuals face a range of disciplinary regimes which attempt to challenge or control their sexual expression. The queer movement and the disability movement also share members. As Eli Clare (1999: 123) has commented:

> Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race . . . everything finally piling into a single human body. To write about any aspect of identity, any aspect of the body, means writing about this entire maze.

A third theoretical implication of this study is the challenge of moving beyond binary ways of conceptualizing impairment and disability. In this regard, an engagement with queer theory might be profitable for disability studies. There are parallels between the impairment/disability divide and the sex/gender divide. Both have been incredibly useful in terms of separating an experience of social exclusion from an experience of biological difference. However, both of these conceptual distinctions can be accused of containing problematic exclusions. Queer theory has exposed the flaws in the binary distinction between sex and gender. Similarly, groups like brain injury survivors present a range of challenges to the impairment/disability binary. So much of the data in this study does not fit neatly into a discussion of impairment or disability. It is not just "something in between" impairment and disability (French, 1993) but something else altogether. Queer theory has pointed to the instability of identity—so too does the data from this study. Queer theory is also pointing to the problematic exclusions inherent in a political strategy based on identity politics. The data in this study equally supports this view that an identity politics based around disability is problematic for those people who refuse to identify as "disabled." Many brain injury survivors are in this position.

The next theoretical challenge identified by this study is for disability studies to more fully engage with postmodernism. For all its political merit, the social model remains a grand narrative. It does not sufficiently acknowledge disabled people's plurality of experience. Postmodernism celebrates multiple, composite identities and does not engage in the disciplinary effects of the politics of identity. Disability studies can learn a great deal from this approach. Postmodernism supports an understanding of the experience of "disability" not as reflective of one determinant meaning but rather as encompassing a diverse set of meanings. The implication of this understanding is that political struggles around disability need to be based on a recognition of difference rather than imputed commonalities. Coalitional strategies are particularly important in this respect. They do not imply an absolute celebration of difference per se, but rather, a sensitivity to the power relationships which underpin difference. Postmodernism points to the fundamental need to be critical of constructions which essentialize group identities. It reminds us that identities almost always grow in opposition to other identities, and that we need to be sensitive to the economic, political and cultural forces which are intertwined with these identities.

That is not to deny that minority identities can have affirmative political possibilities and can be important symbolic resources for marginalized communities. Rather, postmodernism points to the limitations of a minority model. The challenge for disability studies is not to abandon identity politics altogether, but rather to reconceptualise disability identities as being based on conflicting and multiple meanings, which are always interspersed with other power relations such as class, gender, race, and so on. Essentialist constructions of disability have made certain kinds of struggles possible. For instance, they have helped to support the growth of a "disability culture" associated with the disability arts movement. However, there are limits to an epistemology which is grounded in a concept of an essential disabled identity—it cannot express all of the experiences around disability. It is normative and exclusionary.

The proliferation of literature on the social model by materialist thinkers (for instance Barnes, 1999; Gleeson, 1999; Oliver, 1990; Oliver and Barton, 2000) also has a number of theoretical implications and limitations. It has meant that a crude reductionism, reminiscent of economic determinism within Marxism, has underpinned much of the literature. This reductionism fails to give due weight to cultural politics. By assuming that "primacy must be given to the mode of production" (Oliver, 1990: 23) insufficient attention is given within such an approach to issues like gender, sexuality, race, and ethnicity. This political position has been criticized for decades—indeed it was one of the major reasons for the formation of the new Left in the 1960s. Gender oppression, homophobia, racism and similar forms of power cannot just be added on to an economistic Marxism as an afterthought.

PRACTICAL IMPLICATIONS

There are a number of important practical implications from this study. Perhaps the most important, and most pressing implication is the need for dramatic changes in the way we respond to the challenge of brain injury. There are many examples in this book where people were made very vulnerable because of flaws in systemic responses to the challenge of brain injury. The issue of medical diagnosis of brain injury has been canvassed at length in this study. Misdiagnosis of the "vegetative" state has led to significant human rights abuses, incarceration in nursing homes, social exclusion, and untold human suffering. People in this study have had years of their lives taken away from them because they were inappropriately diagnosed in this manner. None have ever received compensation for these misdiagnoses. Perhaps you cannot compensate someone fully for likening them to a vegetable. Certainly financial compensation would be a step in the right direction, but it cannot give people back the dignity that has been stripped from them, or the opportunities they have missed while they have been incarcerated. Placement of large numbers of young brain injury survivors in aged care nursing facilities is commonplace, but it is morally reprehensible and indefensible. There is a dramatic need for more suitable rehabilitation facilities, across a variety of brain injuries—from slow to recover individuals to people with mild injuries, and there is a need for timely and ongoing rehabilitation across the lifespan. However in Queensland, such services are generally non-existent or located only in the capital city. There are no services specifically designed for Aboriginal people, even though Aboriginal people have the highest rates of brain injury. Likewise, there is no funding for survivor support groups. Despite the rhetoric of

Disability Services Queensland, brain injury is not a priority. Individuals are still being misdiagnosed, inappropriately placed in aged care facilities, abused, and denied basic human rights.

Nursing home accommodation for young people with ABI is regarded as inappropriate by many survivors. In fact, in early April 2000, our group took part in a national day of action against such inappropriate accommodation. Indeed, members of our group have spoken about the inappropriateness of nursing homes on many occasions. Basically, our group believes that there are a number of reasons why nursing home accommodation is not appropriate for many people with an ABI:

- the staff at nursing homes have very little training in responding to the needs of ABI survivors;
- very little rehabilitation (if any) occurs within nursing homes, so people's emotional and physical health can actually deteriorate while they are there;
- nursing homes tend to be focused on the long-term care of frail and aged people, and not on living with impairments;
- disabled people need to be active in the community and not segregated in institutions;
- the real issue is to ensure there are appropriate rehabilitation facilities which can address people's needs; and
- there needs to be flexibility so that people whose conditions improve can leave any facility and move to one which is more appropriate to their needs.

Nursing home accommodation is considered quite different from slow stream rehabilitation facilities, but even people who are in those facilities find it difficult to move from one level of supported accommodation to another. The need for more flexible supports could not be more evident.

The flaws in the service delivery system have also been highlighted in this study. There is a clear need for services which are flexible, responsive, culturally appropriate, ongoing, and delivered in a timely manner. However, the services that are provided for brain injury survivors are often inflexible, unresponsive, culturally inappropriate, time-limited and (even then) rarely delivered on time. Even more concerning is that many survivors reported that these services were very disrespectful. This is a major problem, given that it is the role of such services to enhance the individual's quality of life. From the data gathered in this study it seems such services may sometimes have the opposite effect. This study is not alone in reporting the deficiencies of the service delivery system. These deficiencies have also been identified in previous Government reports, as was indicated in Chapter Three.

A number of the survivors interviewed in this study had long-term psychiatric issues which were not being addressed in any meaningful way. Some went in and out of psychiatric institutions, as if they had a revolving door. Others dealt with post traumatic stress, depression, suicidal ideation and engaged in self-harm without any social or medical support. It is simply unacceptable to see such a criminal neglect of basic human needs. The service system must be more responsive to these issues. Survivors must be thoroughly involved in this process. As we have seen in this book, survivors can make an important contribution to the lives of other survivors. Simply knowing someone else who has been through similar issues can be an important safeguard for a vulnerable individual. The participants in this study had gained knowledge, information, friendship and solidarity from such networks.

One of the challenges which the participants in this study have faced is the struggle to reassert their own identities. Language has been a particularly important aspect of this struggle—people have wanted to be known as "survivors" rather than "tragic victims." There are major practical implications of this struggle. Once someone receives a brain injury, they often find themselves faced with a barrage of power structures, which impose other people's definitions of their needs and problems. The personal competence of the individual is assumed to be irrevocably damaged. Choosing to self-identify as a "survivor" and to struggle to assert some level of control over one's life are therefore major acts of resistance for many people with a brain injury. Being a "survivor," with the right to participate fully in any decisions that affect your life, is an empowered status. It challenges the conventional wisdom that brain injury survivors "lack insight" into their own condition.

Such conventional wisdom depicts people with a brain injury as incapable of managing their own affairs, and placed under the control of others "for their own good." This process of domination has a circular logic to it. People who are frequently told they are incapable of managing their own affairs may one day come to believe that such statements are true. Fortunately, many of the survivors in this study have not internalized their oppression to that extent. That is not to deny that people with a brain injury may sometimes display unpredictable behavior or a lack of control, but it is to position them as human beings whose rights need to be acknowledged and respected. Whether or not people use the language of "citizenship," their discourse is explicitly concerned with the relationship between brain injury survivors, their communities, and the governments which define the conditions under which they receive support. Therefore these struggles should be of concern to anyone with an interest in social justice. Empowerment requires changes in people's lives, in the disability support system, and changes in society.

METHODOLOGICAL IMPLICATIONS

This book has grappled with two overlapping methodological considerations:

- How has my position as an "insider" effected the research process?; and
- Can disability research be "emancipatory," and if not, can it be non-exploitative?

Rather than assuming that I know a great deal about the topic because of my experiences as an "insider," I have consistently problematized that position. I have refused to take a binary approach to the "insider/outsider" question. Instead, I have noted the differences between myself and the other research participants in terms of age, education and social position and I have continuously sought to examine my own influence on the research material. I have actively sought out discrepant data and have engaged in a number of validity checks. This approach to "insider" research, with its increased emphasis on methodological rigor, can be applied by other researchers as long as they recognize the multiple ways in which the researcher is positioned relative to research participants and adopt a rigorous methodological approach to data collection and analysis.

In terms of the disability literature on "emancipatory" research, I have expressed a number of concerns over the rhetoric of "emancipation," because of its essentialist undertones. Nevertheless, I have consciously sought not to harm or exploit the participants and I feel that I have made some positive contributions to their lives. While Ron was still in the nursing home, I was able to encourage a number of other survivors to visit him and was able to publicly advocate for his release from what he called his "jail." Eventually we were successful and he now lives in the community. I was also able to support Duncan and Jill in the process of applying for lifestyle support. They were successful in receiving a limited amount of money from Disability Services Queensland (DSQ). Another positive outcome that I have been able to work towards is a dialogue between some survivors and DSQ. At the beginning of this project, no such dialogue existed. I wrote an open letter to the (then) Minister for Family Services, Ms. Anna Bligh, halfway through this research project. I distributed this letter on the Women

With Disabilities Australia (WWDA) email discussion list, and other people forwarded it to their own discussion lists. I was astonished by the results. One of the issues I had raised was the way DSQ ignored the needs of women who had received their brain injuries through domestic violence. Eighty-seven women in this situation contacted me, and voiced their concerns about the neglect of this area by DSQ. A number wrote letters to the Minister themselves. WWDA took up this issue and campaigned on it. Some changes in public policies, albeit tokenistic, have resulted. There is now an official consultative group on brain injury which has been established in the political fall-out from this campaign.

Another positive outcome has been the changes in Rick's life as a result of throwing himself whole-heartedly into the struggle of brain injury survivors. He is now involved in the DSQ Consultative Committee, and has established links with a number of disability groups including Queensland Advocacy Incorporated. He has also become an active member of the "Young People in Nursing Homes" campaign. Rick now has contacts with brain injury survivors throughout the entire State, mostly conducted via email. This research project has assisted him to make some of those connections.

One woman who participated in the project told me that I was the only person who had ever supported her emotionally. My house has been the "safe house" she comes to when she needs to escape domestic violence. That may not be a "grand" outcome, in terms of the overall goals of "emancipatory" research, but it is significant to both of us. She is a vulnerable person and I have made a difference in her life. She is still oppressed, but she has found one "safe" place where she is not under physical or emotional attack. Making my house available to participants has meant that I have an unorthodox relationship with them. This requirement has meant that I had to be careful in deciding what was, and what was not, a part of the research. Ethically, I dealt with this challenge by being careful about which data I discussed and by showing all the participants my papers before they were shown to anyone else.

In terms of political outcomes, I have been able to organize a number of meetings between survivors and representatives of DSQ during the course of this research. I, alongside other survivors, also wrote a petition to Parliament. In an ideal world, I would be able to write about the way these actions led to significant change. Unfortunately, what they really involved was a process where many participants "got their hopes up" and were eventually bitterly disappointed. People were asked to go to meetings with DSQ, but no real changes occurred and they left demoralized. After a number of months, many participants began to indicate that they had no faith in the negotiating process. DSQ was seen as the symbol of their oppression, and many participants indicated they felt that the people in charge of DSQ were only prepared to engage in tokenism. Naturally, they lost a great deal of enthusiasm for the process. It will be even more difficult for DSQ to engage in meaningful dialogue in the future because of the tokenistic approach they have adopted over the past few years.

AREAS REQUIRING FURTHER RESEARCH

One of the important findings of this research is that a number of people are misdiagnosed as being in the "vegetative state." There needs to be immediate research into the numbers of people in this situation. Each person who has been misdiagnosed in this way has lost a great deal of their citizenship rights. This human rights abuse must not continue. We need to know how many more people like John have been locked away and forgotten. Once research is conducted into how many people are in this situation, funds must be made available for their release from the nursing homes and the other places where they are currently incarcerated. Such people will need to be supported to live in the community. Perhaps the individuals who have been improperly incarcerated in this manner should be supported by disability groups to take a class action and sue the State for neglect.

Another area requiring further research is the service delivery system in the brain injury field. Dominated by traditional disability organizations which adopt a charity approach, the service system has come in for a great deal of criticism from some participants. In order to find out the extent to which such dissatisfaction is widespread, further research needs to be conducted. The small sample size in this project does not enable me to make any predictions about the representativeness of the views expressed by participants.

The needs of people from Non-English Speaking Backgrounds with a brain injury is another topic deserving further research. Madonna's story, which reflected an inability to access any culturally appropriate information or services, is particularly alarming. The health and disability system needs to be more responsive to this community. At the moment, there are no organizations in Brisbane which focus on providing disability services to people from diverse ethnic backgrounds. This situation must also be rectified.

CONCLUSION

This book has pointed to the need for some important practical revisions in the way we understand and respond to the experience of brain injury. But it has also pointed to the merit of an interdisciplinary approach to the study of disability, impairment, embodiment and identity. Drawing on feminism, queer theory, postcolonial and postmodern literature, the book has suggested that disability studies needs to adopt a more critical approach to the impairment/disability divide and to disabled/nondisabled categories of identity. I never intended this book to answer all the questions people might have about brain injury. It is intended to stimulate debate, to challenge notions that have often been taken for granted, and to promote an interdisciplinary exchange of ideas. This book has been motivated by my own experience of brain injury, but through my connections with the survivor network, I have been able to discuss this research with other brain injury survivors, not only in Australia but also in New Zealand, Canada, America, and the United Kingdom. I know that similar battles are being waged at the local level in many other corners of the globe. I have heard many stories of maltreatment and abuse. Often my own position within the movement has meant that I have had to confront the bureaucracy, and even confront disability organizations. This has been quite an emotional ordeal, at times. I have often felt like I was struggling to retain my own dignity, and not just hearing the stories of other people with similar injuries who had been abused and maltreated. What has kept me going is knowing that there are many brain injury survivors and allies who are prepared to fight for an alternative vision, where we have rights, choices, and respect.

Notes

NOTES TO CHAPTER ONE

1. The use of the term "survivors" in the context of brain injury will be explored in more detail in Chapter Seven.
2. Hevey (1992) explains the difference between such a "charity" model and the social model of disability.

NOTES TO CHAPTER TWO

1. Unfortunately, the role of individuals with a brain injury in this process is greatly under-estimated.

NOTES TO CHAPTER SEVEN

1. Clearly, there are overlaps between brain injury survivors and psychiatric system survivors. There are many people with brain injuries who have psychiatric impairments. However, in terms of formal organizations, each impairment group also has its own unique identity. As Barnes and Bowl (2001) have noted, the concerns of psychiatric system survivors often revolve around the need for changes in the mental health system and treatment in compulsory care settings. However, brain injury survivors are often more concerned with the different institutions in which they find themselves, such as aged care homes. Also, it is important to note that some of the central concerns of brain injury survivor groups (such as the controversy surrounding diagnosis of the "vegetative state") have not been widely taken up by other disability organizations, including organizations representing psychiatric system survivors.

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